

# **The Ethics of Scarce Health Resource Allocation: Towards Equity in the Uganda Health Care System**

**John Barugahare**

**Student No. 201751**

**FILO350**

**Thesis submitted in partial fulfilment of the requirements for the  
Degree of Master of Philosophy at the Faculty of Humanities, University of  
Bergen, Norway**



**May 2011**

© 2011

Copyright by **John BARUGAHARE**

All rights reserved.

Advisor:

Prof. **Reidar K. Lie**

## **DECLARATION**

I, John **BARUGAHARE**, hereby declare to the Department of Philosophy, Faculty of Humanities - University of Bergen, that this work is original and a result of my own effort, except where acknowledged. I also declare that to the best of my knowledge, this work has never been published or submitted to any university or institution for examination purposes.

## **Dedication**

To

Maria Gorret Korukanga

&

Savino Katsigaire

## **Acknowledgements**

I acknowledge all the support – moral and material - received from my mentors, friends, parents and relatives. It is this support that has enabled me get to this level. Unfortunately, I can not mention everybody's name in the all the categories listed, but some names are unavoidable.

I am highly beholden and thankful to my mother Maria Gorret Korukanga and my uncle Mr. Savino Katsigaire whose initial material and moral support alone was enough to get where I am now and wherever and whatever good I will be. I acknowledge the generosity of Uncle Kandebe Jeffrey Ntambirweki, who made a very big sacrifice to pay for my initial return-ticket to and from Bergen. I am really very grateful. And, from the deepest of my heart I, in a special way, acknowledge the patience of my wife (Mary Kankunda) and my son (Valentine Karuhanga), for all the two years I have been physically detached from them. I am grateful for Mary's encouragement and love that made me feel, not withstanding thousands of miles between us, that we were always together.

I also must extend my thanks to my professional counsellor, Dr. A.B. Rukooko (Dean of Liberal and Performing Arts, Makerere University). It was because of his encouragement and care that I pursued and finally got admitted to this program. In this regard, I can not forget to recognise in a very special way, the professional and motherly care, imbued in kindness, extended to me by Vigdis Songe-moller, the leader of the institute of Filosofi at the university of Bergen. It was because of her personal effort that I was miraculously admitted to this program at a time when the whole institute of Filosofi had not been given a single slot for

the Quota scheme. It was 100% out of Vigdis' lobbying that my application was finally accepted and registered by the University of Bergen.

I also wish to extend my warm thanks to the Government of Norway through the Norwegian State Educational Loan Fund (Lånekassen), for accepting to fund my studies at the University of Bergen, on top of meeting all my travel and living expenses.

Finally, and most importantly, I must say that it is always one thing to get admitted to a program and it is another to successfully complete it, moreover in normal time. Therefore, I can confidently say that all the contributions acknowledged above would have been wasted if I did not have an advisor whom I have come to regard as an ace. I feel so grateful and indebted to Professor Reidar K. Lie for his commitment, guidance and patience especially wherever I might have seemed off-track. His very critical and constructive comments during my study at UiB always made me believe that I am very close to the best thing possible in my work. This is truly the best motivation strategy I can conceive and I have ever received from any advisor. Once again I remain so grateful and indebted to you Professor Reidar K. Lie.

<b>Table of contents</b>	<b>Page</b>
Declaration .....	3
Dedication .....	4
Acknowledgements .....	5
List of Acronyms .....	11
List of figures .....	12
Abstract .....	13
Abstrakt .....	14
Introduction .....	15
<b>CHAPTER ONE: The Uganda Health Care System: An overview. The Extent and</b>	
Distribution of Health Deprivation .....	23
Introduction .....	23
Background .....	23
Historical context .....	23
Current status .....	24
The structure of the system .....	26
Goals, Aims and objectives of the health system .....	27
Objectives .....	27
Value-based Objectives .....	29
Health care Financing: The Extent of Deprivation .....	29
Introduction .....	29
Financing and Management .....	30
Deficits for health.....	34
Introduction .....	34
Is Health Deprivation Equitably Shared? .....	36

Introduction .....	36
Meaning of equitable financing .....	37
Financing mechanisms and implication for equity.....	38
Priority setting in health.....	41
Ethical Principles .....	41
Priority Interventions .....	43
<i>Health promotion and education</i> .....	43
<i>Disease prevention program</i> .....	44
<i>Early Diagnosis and Treatment</i> .....	44
<i>Other Priority Areas</i> .....	44
Primary Health Care (PHC) .....	45
Conclusion .....	46
CHAPTER TWO: Utilitarianism in Health: the use of QALYs in Health	
Rationing .....	48
Introduction .....	48
The Theory of Utilitarianism .....	49
QALY – What it is .....	51
Utilitarianism’s Influence on QALY Approach.....	51
Evolution of QALY .....	52
Determining Health Utility .....	53
Estimating QALYs .....	53
Methods used to determine Health Preference Values .....	55
The EuroQoL five dimensions method (EQ-5D) .....	56
The Visual Analogue Scale (VAS) .....	56
The Standard Gamble technique (SG) .....	58
Time Trade-Off .....	59
The person Trade-off Technique (PTO) .....	61



Calculation of final QALYs .....	62
Determining cost effectiveness using QALYs .....	63
The Moral Status of QALYs in Health Rationing .....	66
Justification of using QALYs .....	64
Doubts about the Moral status of QALY .....	66
Doubts from Technicality .....	66
Doubt from Theoretical Underpinning .....	68
<i>QALYs and the value of health</i> .....	69
<i>Life Years versus Lives</i> .....	71
<i>Priority to the worst off compromised</i> .....	74
<i>QALY is anti-egalitarianism</i> .....	75
<i>Aggregation of health output</i> .....	76
<i>Defending QALY's Aggregation</i> .....	77
Social Aversion for QALY Maximisation: Empirical Evidence .....	79
2Conclusion .....	79
 <b>CHAPTER THREE: Criteria for Rationing Health Resources: Ethical</b>	
<b>Dilemmas</b> .....	81
Introduction .....	81
Background .....	82
<b>Part I: Substantive Moral Principles for Health Rationing</b> .....	83
Treating people equally .....	84
<i>Allocation by Lottery</i> .....	84
<i>First-come First-served</i> .....	85
Prioritarianism .....	85
<i>Sickest-First Criterion</i> .....	87
<i>Youngest-First criterion</i> .....	89

Saving most lives versus life years .....	89
Fair chances and best outcomes .....	91
Instrumentalist views .....	93
<i>Promoting Social usefulness</i> .....	94
<i>Rewarding social usefulness</i> .....	94
Allocation by ‘Need’ .....	95
<i>Need as ill health</i> .....	95
<i>Need as Capability to benefit from treatment</i> .....	95
<b>Part II: The Complete lives system</b> .....	97
Objections to the complete lives system .....	101
<b>Part III: The fair procedures option</b> .....	106
<i>Publicity</i> .....	106
<i>Relevance</i> .....	106
<i>Revisability and appeals</i> .....	106
A critical reflection on the Fair procedures proposal .....	107
<i>Controversies and contradictions</i> .....	107
<i>‘Fair Procedures’ and the case of implicit/explicit rationing and Trust</i> .....	108
Conclusion .....	111
<b>CHAPTER FOUR: CONCLUSION</b> .....	113
Introduction .....	113
Poverty and inequity in health .....	115
The missing link .....	117
Recommendations .....	119
Conclusion .....	120
References .....	123
Reading List .....	133

## **List of Acronyms**

CEA	Cost Effectiveness Analysis
DALY	Disability Adjusted Life Years
FY	Financial Year
HRQoL	Health-Related Quality of Life
HSSP	Health Sector Strategic Plan
HUI	Health Utilities Index
MoH	Ministry of Health
MoLG	Ministry of Local Government
MTEF	Medium Term Expenditure Framework
NHS	National Health System
PHC	Primary Health Care
PHP	Private Health Practitioners
PNFP	Private Not For Profit
PPP	Purchasing Power Parity
PTO	Person Trade-Off
QALY	Quality Adjusted Life Years
QoL	Quality of Life
SG	Standard Gamble
TCMP	Traditional and Complementary Medicine Practitioners
TTO	Time Trade-Off
UNMHCP	Uganda National Minimum Health Care Package
VAS	Visual Analogue Scale

## List of Figures

Figure 1: An Illustration of a Visual Analogue Scale .....	p. 54
Figure 2: An Illustration of a Standard Gamble Decision Tree .....	p. 55
Figure 3: An Illustration of Time Trade-Off .....	p. 57

## Abstract

The central ideas in this work are *health as a moral entitlement* and *equity in health*. It is a discourse on distributive justice in health and takes Uganda as a case study. It describes Uganda health system especially the *extent* and *distribution* of health-related injustice brought about by severe poverty and the manner health resources are raised and allocated. This manner disproportionately adversely affects the poor's access to health services and endangers their livelihoods due to catastrophic health expenditure. This work further critically reviews the theory of utilitarianism (QALYS) which is popularly used in the allocation of scarce health resources. Utilitarianism is accepted as good for ensuring efficiency in health resource allocation, but not good enough to ensure equity in health. This being the case a discussion of other ethical principles of health resource allocation that attempt to close the 'fairness gap' left by the theory of utilitarianism becomes necessary. Having critically examined QALYs and other moral principles, it emerges that a discourse on these per se is good but not good enough to guarantee equity in health in Uganda, even if a harmony between these suggestions were found. The main reason for this is that the said discourse is based on a subtle, yet wrong assumption, that all health services in Uganda are financed by the state and therefore health equity would be achieved if those resources are equitably distributed. This assumption ignores the fact that due to severe poverty and a very steep social gradient, out-of-pocket payment for health services is a prohibitive factor in the use of private health services. This leads to unequal access to health services between social classes since 50% of health out-put is from the private health service providers, hence must be paid for. This points to the fact that there is a strong spiral cause relationship between poverty and health inequity, the fact that is ignored in the discourse on QALYs and other allocation principles that aim at health equity. Therefore, since the poor are disproportionately adversely affected in the current system, developing an equitable financing mechanism for the health care system which takes into consideration the special needs of the poor should be a key priority in Uganda.

## Abstrakt

Den sentrale ideer i dette arbeidet er helse som en moralsk rett og egenkapital i helse. Det er en diskurs om rettferdig fordeling i helse og tar Uganda som en casestudie. Den beskriver Uganda helsevesenet spesielt omfanget og distribusjon av helse-relaterte urettferdigheten skapt av alvorlig fattigdom, og den måte helseressurser er hevet og fordeles. Denne måten uforholdsmessig negativt påvirker de fattiges tilgang til helsetjenester og truer livsgrunnlaget på grunn av katastrofale helseutgifter. Dette arbeidet videre vurderinger kritisk teorien om utilitarisme (QALYs) som er populært brukt i fordelingen av knappe helseressurser. Utilitarisme er akseptert som bra for å sikre effektivitet i helse ressursfordeling, men ikke gode nok til å sikre egenkapitalen i helse. Dette blir tilfelle en diskusjon av andre etiske prinsipper for helse ressursfordeling som prøver å lukke 'fairness gapet "til venstre ved teorien om utilitarisme blir nødvendig. Å ha kritisk undersøkt QALYs og andre moralske prinsipper, framgår det at en diskurs på disse i seg selv er bra men ikke god nok til å garantere egenkapitalen i helse i Uganda, selv om en harmoni mellom disse forslagene ble funnet. Hovedårsaken til dette er at nevnte diskursen er basert på en subtil, men likevel feil forutsetning, at alle helsetjenester i Uganda er finansiert av staten, og dermed helse egenkapital ville oppnås dersom disse ressursene blir rettferdig fordelt. Denne antakelsen overser det faktum at på grunn av alvorlig fattigdom og en veldig bratt sosial gradient, ut-av-lomme betaling for helsetjenester er en uoverkommelige faktor i bruk av private helsetjenester. Dette fører til ulik tilgang til helsetjenester mellom sosiale klasser siden 50% av helse-utgang er fra det private helsevesenet tilbydere, dermed må betales for. Dette peker på det faktum at det er en sterk spiral årsak sammenhengen mellom fattigdom og helse urettferdighet, det faktum som er oversett i diskursen om QALYs og andre tildeling prinsipper som tar sikte på helse egenkapital. Derfor er fordi de fattige uforholdsmessig negativt påvirket i dagens system, utvikle en rettferdig finansiering mekanisme for helsevesenet som tar hensyn til de spesielle behovene til de fattige bør være en prioritet i Uganda.

## Introduction

This work is a discourse on distributive justice/equity in health and it takes Uganda as the case study. The underlying concept of this work is *health as a moral entitlement* to which all human beings are equally entitled by virtue of their moral equality. Hence, any deprivation to this entitlement is a moral evil and much less if it is unequally distributed among the citizens. The conception of health as a moral entitlement is drawn from Aristotle's conception of the citizen's moral entitlement to conditions that enhance human capabilities.<sup>1</sup> In Nicomachean ethics, Aristotle argues that the state (law-giver or ruler) has a moral duty to ensure that the citizens can afford a good and flourishing life or to be able to function properly; and his search for the good is a search for the highest good. Although this highest good (desirable for its own sake - a virtuous life) is not health, Aristotle makes it clear that on top of striving to live a virtuous life, in order to be happy one must possess other goods as well - such as good health among others. And one's happiness is endangered if one is severely deprived in such advantages - for example, one has lost children or good friends through death (Aristotle, (1099a31-b6)). The reason for the pursuit of these contingent human goods other than a virtuous life is that one's virtuous activity will be to some extent diminished or defective, if one lacks an adequate supply of other goods (Aristotle (1153b17-19)). Someone who is in a very poor health state, (un educated, without friends) et cetera, will simply not be able to find many opportunities for virtuous activity over a long period of time, and what little he can accomplish will not be of great merit. Hence, drawing on Aristotle's argument that the citizens possess moral entitlements to those things that enhance their proper functioning, and health care being one of them, it follows, on Aristotle's account that, health care is a moral

---

<sup>1</sup> Drawing on Aristotle and Marx, Nussbaum claims that for a person to be able to live a life worthy of the dignity of the human being entails that she possesses certain capabilities that represent various kinds and amounts of activity and opportunity. These central human capabilities each 'above' a specified threshold all-inclusively constitute a level of substantive freedom to pursue one's own ends in such a way that is commensurate with the dignity of the human being. (Nussbaum, 2006).

entitlement.<sup>2</sup> Hence, although health is not to be conceived as an ultimate good or be conceived to have an intrinsic value, human beings have a moral entitlement to that which makes their virtuous life possible. For this reason, severe deprivation of health is seen as unjust and worse still if this deprivation is inequitably shared among those that suffer it.

Regarding the distributive conception of these enabling conditions for a good and flourishing life, Aristotle argues that “It is evident that the best *politeia* is that arrangement according to which anyone whatsoever might do best and live a flourishing life” (Nussbaum 1987:2). For that matter therefore, “It is the job of the excellent law-giver to consider, concerning a city and a class of human beings and every other association, how they will partake in the flourishing living that is possible for them”(Nussbaum 1987:2). Equally, it has been argued that within democracies citizens should be able to participate in decision making about issues which affect their vital interests. Access to appropriate health care is clearly one of the most important of such interests. On the face of it, therefore, if justice in health is to be realised, the way in which scarce health care resources are distributed between those who need them is an obvious candidate for a democratic mandate. It is for this reason that in attempting to come to grips with the moral problems posed by the necessity for health care rationing, governments of different countries have endorsed the importance of public participation in setting priorities in health care spending (Cooper, Coote 1995:1).

In the history of political philosophy, from the ancient times to the present, a number of theories of distributive justice have been formulated and discussed. However, in this work I have no intention of discussing or listing all of them. This work considers at length, one of

---

<sup>2</sup> This argument has been further extrapolated and developed by Amartya Sen and Martha Nussbaum in their capabilities approach to health care entitlements. It has further been a basis of a human rights approach to health and a basis by the World Bank and the World Health Organisation to demand that all countries should define certain amount of health care called the Minimum Health care package. This minimum health care is expected to be enough to enable basic human functionings.



these ethical theories that has been widely debated in health care discourse regarding health resource allocation. The theory considered in this case is *utilitarianism*. Further, theories such as egalitarianism and prioritarianism are also briefly reflected upon with the intention of filling the ‘fairness gap’ left by the theory of utilitarianism in health resource allocation. Those who advance other theories apart from utilitarianism, such as egalitarianism, prioritarianism among others, argue in favour of equal chances of being healthy or ill. On the converse, those who endorse utilitarianism in health argue that health policy should be designed to maximise health benefits from a given budget, no matter how fairly or unfairly those benefits are distributed among the people.

This discourse is founded on the normative position that, the way health policy is designed particularly regarding priority setting amidst scarce resources and endless health needs, should lead to equitable distribution of health benefits and burdens. This position has been motivated by the general agreement that health services throughout the world do not have enough resources to meet the health care needs of all of their citizens. Therefore, some form of rationing within health services is inevitable (Ham, Janovsky 1996:25-41). Even within health care systems in which access to health care is guaranteed - however they are funded- this will mean that some who are ill will not necessarily receive treatment when they need it, if at all. Hence, the moral quality of health care delivered in such circumstances of scarcity will depend on the fairness and justice with which such decisions are made (Doyal 1998:98-102).

The scarcity of health resources is more severe for developing countries like Uganda, and this has compounded the severity of deprivation to health entitlements. It is this scarcity of

resources that makes health systems decide to go utilitarian with the aim of achieving the maximum health benefits possible with the available resources.

The process of priority setting has had a number of ethical controversies that call for critical reflection. The controversies are between those who endorse utilitarianism to the effect that no matter what, health systems must strive to maximise health benefits from a given budget. Hence, the advocates of this position advance what they call ‘Quality Adjusted Life Years’ (QALY) approach, which is based on utilitarian principles, as the only appropriate tool for health policy analysis since it ensures efficiency. On the other hand, those who are more bent to principles of justice argue that equity in health is as important as efficiency. Hence, not only the amount of health benefits matters but also how fairly these benefits are distributed. But still, those who believe that equity is a very important aim of health service delivery have advanced conflicting ethical principles they think would lead to equity in health. As a solution to these competing ethical principles of allocation, a set of principles has been suggested in what has been called the *Complete Lives System* which combines a number of these principles. Further, the complete lives system has not passed without challenges. And moving away from the controversial substantive ethical principles, another suggestion has been given aiming at equity in health. This suggestion is the ‘Fair Procedures’ approach in what is now popularly known as Accountability for Reasonableness (A4R). This has itself proved circular in a sense that such a project would be impossible without making reference to the substantive ethical principles which it purports to bypass.

The discussion in this work is taking place with reflections on Uganda’s health system especially the extent of health deprivation and how unjustly this burden is distributed. The problem of health-related injustice in Uganda is compounded by the extent of poverty which

implies severe scarcity of health resources. As noted above, scarcity of health resources is an obvious and glaring challenge world-wide – even within the high income countries like Norway. Hence, whereas other countries like Norway are reckoned to be under-deprived in terms of health and the social determinants of health, there also is said to be scarcity of health resources. This gives a clear picture of how severely deprived a low income country like Uganda is in terms of health. For instance, in the case of Uganda, the gross national income per capita (PPP international \$) is 880 against 50,070 for Norway; Life expectancy at birth m/f (years) stands at 49/51 for Uganda against Norway's 78/83; Healthy life expectancy at birth m/f (years, 2003) is 42/44 for Uganda while that of Norway stands at 70/74. Further still, in Uganda, the probability of dying under five (per 1 000 live births) is 134 and that of Norway is 4; and that of dying between 15 and 60 years m/f (per 1 000 population) is 518/474 for Uganda against Norway's 86/53. For the case of Uganda, total expenditure on health per capita (Intl \$, 2006) is at 143 compared to 4521 for Norway (WHO, 2008).

For that matter, therefore, in this work I will partly endeavour to show in some detail, the extent of Uganda's health deprivation and its unequal distribution due to experiences of extreme poverty and income distribution which is extremely unequal. I will do this because it is important to note that due to the fact that Uganda's health sector is severely underfunded, 50% of health services are financed out-of-pocket by households; and for this reason it has been found out that that on average, 9% of households incomes are spent on health services which means that, given the level income disparities in the economy the poor must be spending about 30% of their income on health. And as a consequence of this, nearly 5% of the households in Uganda are experiencing catastrophic payments while 2.3% are impoverished because of medical bills (Government of Uganda, MoH 2010).

Generally, in chapter one of this thesis I argue that Uganda is severely deprived of health entitlement due to the severe underfunding of the health system. I will also argue that the injustice in the Uganda health care system is further compounded by inequitable distribution of this deprivation due to the system's financing mechanisms which are inequitable and fragmented, and that there are not yet systematic efforts to avoid this injustice. In chapter two where I discuss the moral relevance of utilitarianism in health resource allocation, my analysis reveals that in the face of severe deprivation like one in Uganda as elsewhere in the developing world, there is nothing inherently wrong with endorsing the theory of utilitarianism with its consequent 'health-benefit-maximisation' as a guiding principle in the allocation of health resources. I indicate that this theory can however be treated with suspicion if it ignores concerns of distributive justice in health. After this I go ahead to show how utilitarianism and its consequent QALY maximisation indeed ignore issues of distributive justice, hence needing supplementation and mitigation from other ethical principles. In chapter three I present a critical discussion of these other ethical principles and further argue that, of these ethical principles suggested for allocation of health resources, still none of them on its own takes care of all ethical values that need to be considered for the sake of balancing equity and efficiency. I also discuss the suggestion made by Persad et al: that is, a combination of a number of morally relevant principles in what they call the *Complete Lives System*. I also consider Norman Daniel's proposal of the *Fair Procedures* approach and its challenges. In the conclusion (chapter four) I indicate that, even though it is worth the effort to try to come up with approaches and ethical principles for the allocation of the available *public* resources, this is not enough to guarantee health equity in Uganda. The reason given is that the discourse on these approaches and ethical principles miss the fundamental cause of health inequities in low income countries which is poverty and its impact on access to health, given the financing mechanisms of health services in these countries. I conclude that since

utilitarian-based QALY approach and all ethical principles ignore the fundamental cause of health inequities in Uganda which is poverty and the financing mechanisms of the system, developing an equitable financing of the health care system which takes into account the needs of the poor should therefore be a key priority.

## **Chapter 1**

### **The Uganda Health Care System: An Overview**

#### **The Extent and Distribution of Health Deprivation**

##### **Introduction**

In this chapter I will present an overview of Uganda's health care system as a basis of analysing the relevance of the major ethical theory, *utilitarianism* and its consequent QALY approach regarding health resource allocation. In this chapter, three main arguments are presented: The first argument is that Uganda is severely deprived of health-related entitlements and this is because the health sector is severely underfunded. I show that as a consequence of underfunding, there is a lot out-of-pocket payment for health services by the public in order to cover the deficit, and this has negative implications for equity. I will do this by providing figures that indicate the level of deprivation such as budget allocations to the health sector and the deficits therein. For this purpose I will also indicate how much the individuals are affected by catastrophic health expenses due to lack of essential drugs in public health facilities. I argue that the ultimate outcome of this arrangement, the whole system has evidently disproportionately negatively affected the poor's access to health services and has endangered the poor household's livelihoods and this is further compounding the health injustice in Uganda.

The second point of this chapter is an attempt to show that health entitlement deprivation in Uganda is inequitably distributed. I will argue that this is because of the fact that Uganda health care financing system is inequitable and fragmented and it disproportionately adversely affects the poor. I will do this by exploring the health care financing mechanisms in Uganda and how equitable they are. To make this point clear, I will first show briefly the meaning and demands of equitable financing so that after presenting Uganda's financing mechanisms it

will be easy to tell whether and how much inequitable the burden of financing health care is inequitably distributed.

The third argument is that even though attempts are made in the health policy statements about prioritisation in an attempt to equitably share this deprivation, there is still lack of systematic effort to health care rationing. I will make this point by examining real priority setting practices in the health sector to find out how systematic this process is. I will indicate the scope of the priorities in the Uganda health care and argue that since everything about health care in Uganda is include in priorities, then the system lacks in systematicity regarding priority setting. I will further show that as a consequence of this, the stated values such as priority to the poor, women and children and equity in general are seriously compromised. Before tackling the above-mentioned three points, for purposes of clearly understanding the health care system in Uganda, I will first highlight a brief background of Uganda's health sector and its general structure.

## **Background**

The background to Uganda's health care system given here is a brief historical context of the Uganda health system since independence (1962), and the current health status of Uganda. It also highlights the structure of the system; that is, the organisation and ownership (how much of the system is public or private).

## **Historical context**

According to the findings by Arudo and Syngellakis in their *Overview on Uganda's Health Care System since Independence* (1962), Uganda had the best performing sector in the region up to the 1970s. "In the years after independence in 1962-1971 Uganda had the best health

indices and the best health care system in the sub-region” (Syngellakis, Arudo 2006). This is attributed to the clear prioritisation and efficient management of the sector during that period. However, after 1971 “Health care service provision was highly fragmented and opportunistic” (Syngellakis, Arudo 2006). As far as prioritisation was concerned, it is noted that before 1971 communicable disease control programmes and research programmes were top on the agenda and were very active, with funding from multi-lateral and bi-lateral donors and research organisations in more developed countries (Syngellakis, Arudo 2006).

Moving from the 1970s and 1980s to the present, the analysis of Uganda’s priority in the health sector indicates that the government’s attention has been primarily focussed on re-establishing a political and economic environment conducive to growth, not improving the health of Ugandans as such. In other words, the health sector in general has not been of priority. The social sector ministries have been less of a priority, with no attention given to developing comprehensive health policy for the country (Syngellakis, Arudo 2006). This partly explains the extent of severity of health-entitlement deprivation in Uganda. It is further shown that health care service delivery has been a key element of many aid programmes, though this is not mirrored by the development of national health policy, which has remained ad hoc and focused on hospital rehabilitation (Syngellakis, Arudo 2006). However, irrespective of commitment to improve people’s health (in political rhetoric), Uganda’s health indicators are very poor, judging from those indicators that are outlined as areas of priority – sexual and reproductive health, child health, health education, and control and prevention of HIV/AIDS, Malaria and Tuberculosis.

### **Current health status**



Information on the current health status in Uganda is crucial to the process of setting priorities in the health sector. Such information include the leading cause and distribution of morbidity and mortality in different age groups, sexes, social status, location – that is neighborhood such as rural against urban populations or slum dwellers against rich-suburb-dwellers. The reason here is that, if a health policy is to be effective, efficient and fair in a way it sets priorities for alleviating health deprivation, it must take into considerations all this data.

According to the World Health Organisation's findings on the leading causes of morbidity and mortality in Uganda, HIV/AIDS is the leading cause, accounting for 25% of all deaths. This affects all age groups. This is followed by malaria, causing 11% of deaths, followed by lower respiratory infections at 11% also, and diarrheal diseases at 8%. The rest of the causes are not so significant and are all below 5%. They include, poor perinatal conditions, tuberculosis which is now more as a result of HIV, cerebral vascular disease, ischaemic disease, measles, and tetanus, respectively (WHO 2006).

According to Uganda's available literature on health care, priority is set out in two aspects. One is in terms of the guiding moral principles and values that will guide the implementation of the health policy, and second is in terms of what type of health interventions will receive the highest portion of the budget and attention in general. On the part of priorities for guiding values and principles, they include ensuring equity in health, priority to the poor, women and children and ensuring accountability – both financial and non-financial. From these moral principles and values, there is derived what health interventions are to receive the highest portion of the budget and attention in general. There are four priority interventions which include sexual and reproductive health, child health, health education and promotion and control and prevention of HIV/AIDS, Malaria and Tuberculosis. This is what is referred to as

the Primary Health care (PHC) for Uganda. Since all these priority interventions need a well functioning health system, and realising that Uganda's health system is not that type at present, a fifth area of priority has been added. "For the above to be achieved the government commits itself to strengthening the health system; hence priority is also given to systems strengthening" (Government of Uganda, Ministry of Health, 2008:43). However, the general statement of strengthening the health system among top priorities makes virtually everything about health becoming a priority. This is most likely to make implementation of such a policy extremely difficult.

### **The structure of the system**

According to Uganda's Health Sector Strategic Plan (HSSP) III, the National Health System (NHS) in Uganda constitutes of all institutions, structures and actors whose actions have the primary purpose of achieving and sustaining good health. It is made up of the public and the private sectors. The public sector includes all government health facilities under the Ministry of Health (MoH), health services of the Ministries of Defence (army), Internal Affairs (Police and Prisons) and Ministry of Local Government (MoLG). The private health delivery system consists of Private Health Providers (PHPs), Private Not for Profit (PNFPs) providers and the Traditional and Complementary Medicine Practitioners (TCMPs) (Government of Uganda, MoH, 2009).

The Uganda Ministry of Health is the overseer of the whole health care system in Uganda. However, even though this is the case, since Uganda adopted a Sector Wide Approach for health care, other ministries have some kinds of responsibilities to fulfil in collaboration with the Ministry of Health (Government of Uganda, MoH, 2009).

As an overall monitor of the system, one among the core functions of Uganda's national health care system is the *stewardship* of the sector including policy appraisal and development, oversight of health sector activities, assuring quality, health equity and fairness in contribution towards the cost of health care, harnessing the contribution of other related sectors, ensuring that the sector is responsive to the expectations of the population (trust) and to be accountable for the performance of the wider health sector. (Government of Uganda, MoH 2008:54)

### **Goals, Aims and objectives of the health system**

According to the Uganda National Health Policy of May 2009, the slogan for the health sector is “Reducing poverty through promoting people’s Health” (Government of Uganda, MoH , 2009:8). Its vision is to have “a healthy productive population that contributes to economic growth and national development” (Government of Uganda, MoH, 2009:8). On the social values to guide the health care delivery, the policy further re-affirms the people’s right to the highest attainable level of health – “the constitution guarantees rights of access for all people in Uganda to high quality health care services (Government of Uganda, MoH 2009:8). Constitutionally, the government of Uganda has an obligation to provide basic medical services to its people and promote proper nutrition. Among its primary objectives is that “The State shall take all practical measures to ensure the provision of basic medical services to the population (Constitution of the Republic of Uganda, 1995: xx). Other social values to consider include solidarity, equity, respect of cultures and traditions of the people of Uganda, integrity and ethics, patients’ responsibilities and accountability.

### **Objectives**

According to the National Health Policy, no general objective(s) are stated for the health policy, other than the goal, mission and vision of the system. Instead, each area of concern has its own objective. For the minimum health care package, for instance, the objective is “To ensure the provision and increase the utilisation of a Uganda National Minimum Health Care Package (UNMHCP), consisting of promotive, preventive, curative and rehabilitative services for all priority diseases and conditions, to all people in Uganda with emphasis on vulnerable populations” (Government of Uganda, MoH, 2009:13). For the organisation and management of the system, the objective is “To strengthen the organisation and management of MoH and district health systems and ensure effective harmony and linkage among the different levels of health care, private and public sectors, and MoH and the autonomous and self-accounting national institutions” (Government of Uganda, MoH, 2009). Most importantly, regarding the financing of the health system, the objective is “To mobilise sufficient financial resources to fund the health sector programmes whilst ensuring equity, efficiency, transparency and accountability in resource allocation and utilisation” (Government of Uganda, MoH, 2009:20), among other health system concerns with their specific objectives.

### **Value-based Objectives**

Health systems generally have various value-based aims and objectives. In the case of Uganda, other than the objectives relating to what needs to be achieved, the Uganda health care system recognises two Value-based objectives in health care service delivery. According to the Uganda National Health Policy and other related literature, *equity* in health is taken as one of the most crucial aims of the system. A lot of efforts have been promised to ensure equity in health. Some of the efforts towards achieving this objective are seen in the attempt to ensure universal and free access to the UNMHCP, though this still awaits realisation. At the same time, equity is not the only major aim of Uganda’s health system. It competes with another

widely accepted aim – *efficiency*. Efficiency has so far been more pronounced in Uganda's health care than equity, according to most Annual Health Sector Performance Reports (Government of Uganda, MoH, 2007). Not limited to the Ugandan health system alone, generally it is never easy to decide which of these two aims is more important than the other. Hence the most successful health system is normally said to be the one that keeps these two aims in balance.

## **Health care Financing: The Extent of Deprivation**

### **Introduction**

So far I have given highlights of the context of Uganda's health system in a historical and present context as well as the basic structure and arrangement of the system. So, in this first main point of this chapter, I will show the extent to which Uganda is deprived of health entitlement. I will do this by examining the financing status of the health system: that is, the amount of financial resources available to the sector and the resulting deficits. Of course, the existence of budgetary deficits imply that the people will not have access to the basic health care that is deemed enough to facilitate their normal functioning; and this is a moral evil since they are morally entitled to this basic health care. The reason for approaching this point by being concerned about the financing status of the health system is the fact that there is a strong relationship between how much resources are available to a health system and access to health services. I will discuss this point in detail in the next point, immediately after this.

The existing inequities in health in Uganda according to previous studies, (Orem, Zikusooka 2010:23) are majorly caused by the manner health care is financed, and also in the deficiencies within the allocation principles. But mainly, these inequities are attributed to the

financing mechanism that the system relies on which involves a lot payment for health care services out-of-pocket.

### **Health Financing and Management**

The way a health system is organised and managed in terms of ownership (private or Public), has a lot of implications on how health as a whole is financed. At an ideal level, it is expected that all that part of the health sector that is under state ownership (public) is free for all citizens. On the other hand, all that part that lies under private ownership is financed by the clients from out-of-pocket. In turn, all this has an impact on health equity – that is, whether all social classes have fair and equal chances of accessing health care services whenever they need them. This is the case because the easiness with which the public can access health services, more especially in a severely poverty-stricken country like Uganda, is a function of how much they depend on the public and private sectors for those services. For that matter therefore, in the case of poverty-stricken societies, all things considered, the higher the dependence on the private sector, the more difficulty in accessing health services, and vice versa.

With the above in mind, it is imperative to note that Uganda's health sector ownership is by both the public and the private sectors, and the health out put for both sectors is shared in the ratio of 1:1. According to the Uganda National Health Sector Strategic Plan III, it is shown that up to the Financial Year (FY) 2008/2009, the public health expenditure as a proportion of government's discretionary expenditure has been relatively stable at around 9.8%, below the Abuja Declaration target of 15%. Note is also taken that there is no user fees charged in public hospitals but health insurance is for a few and largely subsidized by the employers on behalf of employees. Households constitute a major financing source of the National Health

expenditure (NHE), at 49.7%, followed by donors at 34.9%, central government at 14.9% and then the international NGOs at 0.4% (Government of Uganda, MoH, 2010).

The Government of Uganda recognizes its failure to fulfil its moral obligation of providing the planned minimum health care package to its citizens due to inadequacies in financing. As indicated in the Health Policy statement of May 2009, “adequate quantities of affordable, good quality essential medicine and health supplies should be accessible to all who need them. However, this is not always the case. Inadequate financial and human resources, capital investments and management issues have resulted in the public sector being unable to fulfil its mandate of providing medicines to all those who need them” (Government of Uganda, MoH, 2009:6). The consequence of this shortfall in health care financing by the public sector is that there is a lot of reliance on out-of-pocket financing of the health services by the population. Even though there is no payment of user fees in the public health centres, “the shortages therein have increased dependency on the private sector” (Government of Uganda MoH 2010). The general picture of how households are affected by financing their health is that:

Households spend about 9% of their expenditure on health, although no user fees are paid in lower level government health units and general wings of publicly owned hospitals. However, the private sector charges user fees. When medicines are not available in the public sector, patients buy from the private sector. As private health insurance, largely subsidized by employers on behalf of employees is for a few, health expenditure remains high for most households. It is also known that while public health services are largely free many patients pay under-the counter fees in public institutions. Nearly 5% of the households in Uganda are experiencing catastrophic payments while 2.3% are impoverished because of medical bills (Government of Uganda MoH, 2010).

The HSSP III shows that, the private sector plays an important role in the delivery of health services in Uganda, covering about 50% of the reported output. As noted earlier, the private sector generally comprises of the Private Not for Profit Organisations (PNFPs), Private Health Practitioners (PHPs) and the Traditional and Complementary Medicine Practitioners (TCMPs), the contribution of each sub-sector to the overall health output varies widely. The PNFP sector is more structured and prominently present in rural areas. The PHP is fast growing and most facilities are concentrated in urban areas. TCMPs are present in both rural and urban areas, even if the services provided are not consistent and vary from traditional practices in rural areas to imported alternative medicines, mostly in urban areas. The Government of Uganda recognizes the importance of the private sector by subsidizing the PNFP and a few private hospitals and PNFP training institutions.

In all this arrangement, however, the important point to note is that all private health services are financed out-of-pocket, and they account for 50% of the total health out put for the sector. In fact, it could be said to account for much more than this. The reason is that more often, the government attributes some of the out put to itself even if it is from out-of-pocket of the patients: take for instance, when pregnant mothers are asked to buy their own gloves, razor blades, birth sheets et cetera, when they go to government health facilities. Other cases include when a patient is admitted in a government health facility and they have to buy from pharmacies the most expensive drugs prescribed for them. In all these cases as long as the patient goes to the public health facility, the government claims all the out put. It is very likely that the percentage of health sector output that can be legitimately attribute to government is about 30% or less. This is be corroborated by the government's revelation that:



There is inadequate funding to provide the UNMHCP in all facilities as envisaged: the per capita cost was estimated at USD 41.2 in 2008/09 and will be rising to USD 47.9 in 2011/12 (or UGX 2.75 billion) yet the health budget according to the Medium Term Expenditure Framework (MTEF) was estimated at USD 12.5 per capita in 2008/09, demonstrating a shortfall of almost USD 29. This trend has important implications for service delivery during the HSSP III period as it will imply the need for further priority setting, based on the UNMHCP (Government of Uganda MoH, 2010:23-24).

Indeed, if from the above revelation we calculate the percentage of government's contribution to the estimated \$41.2 per capita expenditure on health, it will be discovered that the \$12.5 which was government's contribution to \$41.2 per capita for the Financial Year 2008/2009, is only 30.33%. This means that, the households who are the financiers of the private health care sector pay about 70% of the health out put.

It should be remembered that one of the main objectives of the Uganda Government through the Ministry of Health is that the Government of Uganda is committed to improve the health status of its people through formulation of sound health financing policies that can create significant fiscal space in the health sector in the medium term. Even though the Government of Uganda subsidizes the PNFPs and its training institutions and a few private hospitals, the level of subsidies for PNFPs remains low at 20% and rather intermittent. The allocation to PNFP facilities is disproportionately low with the volume of services delivered, and takes little account of changing needs in terms of workload. According to the Health Sector Strategic Plan III, "in order to effectively sustain financing to the health sector, there is a need for improving allocative and operational efficiency, increasing government contribution to the health sector budget and mobilizing community contributions through implementation of the national health insurance scheme" (Government of Uganda MoH, 2010).

## **Deficits for health services**

The purpose of presenting the deficits in the health budget is to show the extent to which Uganda is deprived even of the minimum health care to which all people, by virtue of their equal moral status, have an equal moral claim. By indicating the severity of health-entitlement deprivation in Uganda I intend to paint a clear picture of how much injustice Ugandan citizens are suffering generally.

Generally, when it comes to the amount of resources allocated to the health sector, the health sector is severely underfunded. It has been reported, for instance, that for the financial year 2010/2011 the health budget had been cut from Shs 743.1 billion (USD 313.5million) in 2009/10 budget to Shs 638.3 billion (USD 296.3million). This has further reduced the percentage from 9.8% of the total budget in 2009/2010 financial to 9.7% of the total budget for the financial year 2010/2011. All this is contrary to the African Union Abuja Declaration, which stipulates that governments should allocate at least 15 per cent of their national budgets towards health (WHO, 2000:17). Faced with this severe underfunding, the Health Minister unveiled a tight spending plan highlighting essential drugs that constitute the minimum health care package among the unfunded priorities. In a policy statement to parliament, Dr Mallinga reported that although the ministry is expected to spend Shs 201.7 billion (USD 85.1 million) on medicines and medical supplies; this financial year, for instance, there is a shortage of Shs6.7b (USD 2.8 Million) for essential drugs. Other shortages he cited include Shs4 billion (USD1.6Million) for the Cancer Institute, Shs6 billion (USD 2.5 Million) for medical equipment, Shs1.2b for rehabilitation of 41 hospitals and Shs8.4 billion (USD 3.5 Million) for water and electricity in hospitals (Mallinga 2010).

The policy statement revealed that out of Shs 201.7 billion, Shs140 billion is for HIV/Aids and malaria treatment. These required funds will be needed to buy 250,000 blood bags, facilitate 180 heart operations and recruit 800 health workers with an additional Shs155.5b (USD 65.6 Million) deficit for payment of medical workers. Another Shs 7 billion (USD 3 Million) will be required for the prevention, control and mitigation of epidemics and other public health emergencies in the country. In spite of supplementary funding of Shs 90 billion from the Global Fund to fight HIV/Aids, Tuberculosis and Malaria, a deficit of more than Shs100 billion remains in the health budget this year (Mallinga 2010). Further, under the unfunded priorities, Dr Mallinga has reported that the budget for cancer (Shs 4.1 billion) covers only six per cent of the required amount. Shs 30 billion is needed for infrastructure expansion, Shs 10 billion for research and Shs 6 billion for cancer services to spread all over the country. From the health of ministry's report, it is already evident that critical shortage of essential drugs in the country will put thousands of lives of Ugandans at risk. The consequence of this will be either to finance this deficit through out-of-pocket by the households for those who can afford private health services, or go without the health services needed and yet not funded for the poor.

In Uganda today, "there is a raging debate for increased public spending on health beyond the current \$8 per capita, which is only one-third of what is needed to provide the minimum health care package" (Odaga Lochoro 2006:1). In contrast, however, it has been observed that in Uganda, strict limitations on public spending and sectoral budget seem to be there to stay, given the current political climate. The country's prime interest is economic growth and to be free from interference from external donors in its planning and budget execution processes. Moreover, planners at the Ministry of Finance, Planning and Economic Development (the main powerful advisers to the political leadership), the report adds, are not convinced about

the significance of the health sector in economic development. Accordingly, there is no hope for things to get any better or to lead to significantly more resources to health. Consequently, the health sector has systematic shortages and failures, with almost every intervention and process affected (Odaga Lochoro 2006:1).

## **Is Health Deprivation Equitably Shared?**

### **Introduction**

In the above point I have laboured to show that Uganda suffers severe health-related injustice due to the severe scarcity of health resources. But as I hinted earlier, even though it is an injustice that a society is deprived of health entitlements, there can also be another level of injustice within that society. It is for this reason that I make the following point about whether and how much this deprivation is fairly distributed among the people. But in order to authoritatively say that the deprivation is equitably or inequitably shared, there is a need to have a generally recognised benchmark upon which to make this judgement. It should be noted again that the source of injustice in health in Uganda has been found to be the mechanisms the system relies on for financing. Hence, I will present briefly what it means to say that a health system is equitably financed, and from this it will be easy to see whether and to what extent the burden of health deprivation is equitably shared in Uganda.

According to all Annual Health Sector Performance Reports, the most cited challenge for Uganda's health care sector is inadequate funding. In the case of Uganda this is the major source of inequity in health since it limits access to health services especially for the poor. As said above, the mechanisms of financing health care – say, how much the government pays, how much is paid out-of-pocket, and whether there is universal health care insurance – have serious ramifications for or against equity. The overall comment that can be made about

Uganda in terms of equity in financing health care is an allegation that, considering the demands of equitable financing of health, Uganda's mechanisms of financing are inequitable (Orem, Zikusooka 2010:26). This is the point I want to prove below.

### **Meaning of Equitable Financing**

Equitable financing of health care means that those with comparatively least resources make the least contribution to the health financing not only in absolute terms, but also as a proportion of their resources. It further means that lack of personal resources does not restrict somebody's receipt of health services that are recommended based on prevailing norms and scientific knowledge (Braveman, Gruskin 2003:542). Viewed as such, therefore, equitable financing would increase access to health care for the poor and the near-poor. According to Braveman and Gruskin, equitable financing of health care could also reduce the prevalence and depth of poverty by protecting those who are most vulnerable from impoverishment resulting from health care expenses. This would eventually break the vicious cycle of poverty and ill-health from lack of access to health care, which in turn would reduce inequities in health in the long run. Equitable financing, therefore, is likely to be sustainable only if resources are pooled for those members of society who are healthy and those less healthy, and for the affluent and the poor (Braveman, Gruskin 2003:542).

Equitable financing is said to be based on financial protection, progressive financing and cross-subsidies (Orem, Zikusooka, 2010:25). Financial protection means that no one in need of health services should be denied access due to inability to pay, and households' livelihoods should not be threatened by the costs of health care. Progressive financing on the other hand, demands that contributions to health care funds should be made in accordance with the ability-to-pay, so that those with greater ability to pay should contribute a higher proportion

of their income than those with lower incomes. Cross-subsidies mean that there ought to be flow of resources from the healthy to the ill and from the rich to the poor. Hence, an equitable financing mechanism is one that enhances cross-subsidisation in a sense that it allows for a greater proportion of the population to be covered and has progressive contributions (Orem, Zikusooka 2010:25).

Further, for there to be equity in a health system, one of the conditions is that people with the same health needs receive the same health care. Justice in health care demands that patients, rich and poor, feel the same incidence of the burden of financing health care. For this to be possible, as noted above, the richer patients would be expected to pay a comparatively higher percentage of their incomes in order to subsidise the poor patients, and the healthy should also contribute to the health expenses of those who are ill. This progressive and cross-subsidisation in financing would only be possible if, and only if, all health care, or at least the biggest percentage of it, is under public ownership and is being funded by the government. In a deprived society, it is only under this arrangement that one can say that there is equitable sharing of the burden of health deprivation.

### **Financing mechanisms and implication for equity**

In consideration of what it takes for a system to be said to be equitably financed as shown above, investigation by Orem and Zikusooka about health care financing in Uganda has concluded that “Overall, Uganda’s current health financing is inequitable and fragmented” (Orem, Zikusooka 2010:26). The heavy reliance on out-of-pocket funding and the absence of integrated financing mechanisms in Uganda’s health system result in very poor fund pooling. This poor fund pooling means that among patients of the same health needs, some will receive

care while others will not; and others will receive better health care than the rest. This is inequitable sharing of the burden of trying to alleviate health deprivation.

It is very important to take note that attempts have been made to ensure free and universal access to the minimum health care in Uganda. In 2001, the Uganda government scraped user fees for health services in all government health facilities. But despite the fact that health services are meant to be free for all, the poor quality of services, lack of appropriate medicines in health facilities (Orem, Zikusooka 2010:25) and poor physical access to facilities continue to result in reliance on formal and informal private health care providers (Uganda Bureau of statistics, 2006). Reliance on private health care providers means that the only mechanism available to finance this care is direct out-of-pocket payment for these services.

As it has been noted earlier, 50 percent of the total health expenditure in Uganda is still met by the households (out-of-pocket); this percentage of the total health expenditure is equivalent, on average, to 9% of the expenditure of all households (Government of Uganda, MoH, 2010:23). And given the wide income inequalities in Uganda, with GINI coefficient that equals 45.7 (UNDP, 2009), it means that it is even worse for the poor households and it has been estimated to be at 70% for the last quartile of the population (Orem, Zikusooka 2010). As a consequence of this inequitable financing mechanism, it has been found out that in Uganda nearly 5 percent of households are experiencing catastrophic payments for health services, while 2.3 percent are impoverished because of medical bills.

Further, in a situation like Uganda's where over 50% of the health sector is financed from out-of-pocket, equity remains evidently very difficult to achieve. This is because two patients

of same health need but from different income levels will pay the same amount for health care from the private provider. This is unfair to the poor patients because they are paying a much higher percentage of their income than the rich – the poor feel the biggest incidence of the burden of financing health services. Hence, this reveals that one way in which inequity in health is exhibited in Uganda and which also doubles as the cause of other forms of inequity is the mechanism of how health care is financed.

Yet in another instance, in extreme cases the poor patients fail to pay for treatment and in this case they will not access it or will access less than the rich patients can afford, even if they have exactly the same health needs. This is a compromise of the horizontal equity. A related phenomenon is also true between the populations of urban and rural areas. Even if both of the rural and urban patients were to fully rely on public health care, it would mean that the rural patients will pay more in transport to access health care since a significant number of them (52%) are living farther than five kilometres from the health facilities. In real terms then, they would have paid more in comparison with their urban dweller counterparts. And further, in situations where you find that distance has become a prohibitive factor in the use of health care services, it would mean, as is the case in some parts of Uganda, there will have been inequity in access to health care due to long distances.

Hence, from the above analysis it can be concluded that other than the general health-entitlement deprivation that Uganda suffers at a societal level, there is yet another deeper level of health injustice in Uganda. This injustice consists in the inequitable distribution of this deprivation and since this deprivation is related to the health financing mechanisms, then it is more against the poor. Therefore, for there to be justice within the health system in Uganda, attention needs to be paid to the financing mechanism such that they are protective of the poor.



## **Priority setting in health**

So far I have made two out of the three main points meant for this chapter. In the first place I have shown that Uganda is severely deprived of health entitlements due to the underfunding of the health sector, and this is a moral evil. In the second place I have shown that this deprivation is inequitably distributed due to inequitable financing mechanisms used in the sector, and this compounds the depth of health injustice within Uganda. Having made these two points, my third point which follows below is intended to critically examine Uganda's efforts to equitably distribute this deprivation. This equitable distribution, if tenable, would at least ensure health justice at a domestic level, since justice in this case is about equitable sharing of the burdens and benefits of the system. The attempt to equitably distribute health entitlement deprivation is normally through a process priority setting in allocation of the available scarce health resources. Here, on top of exploring actual priority practices, particularly which health interventions are of priority, I will first indicate the ethical principles are said to guide allocation of health resources, and then later state whether they are reflected in health outcomes.

## **Ethical principles**

According to the Uganda National Health Policy (2009), the ethical principles that are supposed to guide health service delivery are equity and efficiency. The strategy to achieve equity is to be pro-poor and being gender sensitive in favour of women, and being responsive to age by giving priority to the young ones. Geographically, no distinction is made between the rural lot and the desperate slum dwellers on one hand, and the rich urban dwellers on the other.

It is important to note that Uganda, like any other sub-Saharan African country, is a low-income country. The health care-related implication of this economic status is that the country has stringent choices to make on how to spend the available limited resources to meet the extremely high health care needs of its population. Hence, due to extreme scarcity of health resources, priorities are mainly set with a view of achieving the highest health results possible using the available resources; that is, to have a cost effective health care system. Yet, as noted earlier, over-concentration on efficiency has led to the relegation of concerns of distributive justice. Since both of these aims are so crucial for any health system, then it is clear that health care system in Uganda faces one of the most complicated priority setting process. Further it will be noted that because of over whelming urgent health needs of Uganda, it has not been easy at all to come out with clear and consistent priorities. As a result there are no systematic efforts to priority setting as seen in clear contradictions in priority statement in the national health policy and what obtains on the ground.

What complicates the priority setting process in Uganda as opposed to what may obtain in a relatively higher income country like Norway, is the fact that the resources available for Uganda are not even enough to assure all individuals of the minimum health care, since a lot of priority areas are reported to be underfunded (Mallanga 2010). This is shown to be true from the ministry's own evaluation which reported that "Over all, only 26% of sampled health units had continuous availability of the '*indicator medicines*'<sup>3</sup> during the month in which the evaluation was carried out (Republic of Uganda, MoH 2010). This is what makes the business of priority setting in Uganda's health care system even more complex and complicated since it would require revision of priorities which means that new priorities from the already existing priorities must be set.

---

<sup>3</sup> These medicines include "coartem Yellow, sulfadoxine pyrimethamine tab, contrimaxole 480mg tab, Oral Rehydration salt Sachet, medroxyprogesterone injection ("Depo")

However, although distinction is made in favour of the poor, the young and women in principle, in practice there is no specific arrangement to achieve this. For instance, maternal mortality rate is still at 550 out of 100,000 live births, under-five mortality rate is still as high as 134; (Busingye 2011). While regarding children's health ranking world-wide, Uganda holds the 21st last slot out of 189 countries (UNICEF 2009). Hence the situation seems to be the opposite since there are a lot of inequities in access to health care against the poor, children and women. The reason for this is that these groups need to spend a very high portion of their income on health care since the public sector admits lack of essential drugs to cover the priority group of patients. As a consequence, in Uganda poverty is a prohibitive factor in the use of the health services in cases where care is sought from the private health care providers or where there is need to spend a lot on transport to access health services.

### **Priority Interventions**

In most cases the choice of which health intervention to give priority has a direct impact on health equity. For instance, giving priority to interventions that target communicable diseases gives priority to poor population's health, while maternal health and immunisation programs would be prioritising women and children. Hence, other than stating health interventions and the ethical values to guide policy implementation separately as the case is with Uganda, it is possible to combine these two by giving priority to interventions that will enhance equity in health. In the case of Uganda, the following interventions are given priority.

### ***Health promotion and education***

This is regarded as the most cost-effective approach to contain the burden of communicable and non-communicable diseases, injuries and mental health problems. The policy expects

Health promotion and education to address major known health risk factors and health determinants, and is to be delivered through specifically targeted population-based programs involving different sectors like other ministries, schools, media, political leaders, civil society organisations et cetera (Republic of Uganda, MoH 2010).

### ***Disease prevention programs***

The reason for prioritising disease prevention programs is that its coverage like EPI, deworming, vitamin A supplementation, food fortification, Intermittent Prevention Treatment and Prevention of Mother to Child Transmission has in the past not been adequate enough to achieve the expected reduction in disease burden. This is inline with the commitment to put ahead maternal and child health (Republic of Uganda, MoH 2010).

### ***Early Diagnosis and Treatment***

The policy commits the ministry to giving priority consideration to early diagnosis and treatment activities. These shall be expanded through improving access to these health services and awareness of the existence of these services among communities. However, what is controversial is that the policy guarantees treatment for all those who go for early diagnosis (Republic of Uganda, MoH 2010).

### ***Other Priority Areas***

In addition to the above priorities in the Uganda national health policy are the following areas:

- Strengthening district health systems in line with decentralisation through training, technical assistance and financial support.
- Reconceptualising and organising supervision and monitoring, including the clinical supervision of health workers at all levels of government health system.

- Improving the collection and utilisation of data for evidence-based decision making at all levels.
- Establishing a functional integration between the public and the private sectors in health care delivery, training and research.
- Redefining the institutional framework for training health workers. Including the mandate of all sectors, leadership and coordination mechanisms, with the aim of improving both the quantity and quality of health workers' production (Government of Uganda, MoH 2009:11).

### **Primary Health Care (PHC)**

The above listed areas of priority along with the strategies of improving the health care system will be applied in the delivery of the minimum health care package. The Uganda's national health policy commits the government to prioritise Primary health care, usually referred to as Uganda National Minimum Health Care Package (UNMHCP). The UNMHCP involves addressing the earlier said four immediate categories of health needs and causes of the high burden of disease and the resultant high mortality and morbidity (sexual and reproductive health, child health and promotion, and control and prevention of HIV/AIDS, Malaria and Tuberculosis). This is expected to be done through ensuring a steady supply and accessibility to all people of Uganda what is referred to as the essential medicines, elsewhere in this work referred to as the '*indicator medicines*' - "coartem Yellow, sulfadoxine pyrimethamine tab, cotrimoxazole 480mg tab, Oral Rehydration salt Sachet, medroxyprogesterone injection ("Depo") (Government of Uganda MoH 2010:13).

The above is in kilter with the overall objective within the Health Sector Strategic Plan II (Republic of Uganda, MoH 2008:14) framework which is to ensure the availability of

adequate quantities of good essential medicines and health supplies required for the delivery of the Uganda National Minimum Health Care Package at all levels of health care delivery. This has been the general and major objective for the health sector for a long time (Republic of Uganda, MoH 2008:116).

According to the Uganda national drug authority, the goal of drug distribution is “to establish and maintain a distribution system which ensures equitable access to, and constant availability of essential drugs throughout the country (Republic of Uganda, MoH 2002:10).” One of the strategies of ensuring equitable and constant distributions is “to produce guidelines, establish systems and incentives to promote and introduce statutory controls as required for enforcing the equitable distribution of drug outlets (Republic of Uganda, MoH 2002:10). As far as drug financing is concerned, the vision is to ensure that sufficient funds are available to maintain a regular and adequate supply of the required essential drugs and equitable access to these by the population. The objectives here include: to develop and support suitable and sustainable drug financing mechanisms at all levels; to encourage private sector investment in appropriate pharmaceutical service provision and pharmaceutical manufacturing. The strategy to be employed to ensure this is done is by ensuring adequate Ministry of Health budget allocations for procurement of drugs and medical supplies (Government of Uganda, Health Policy 2009:20).

Given actual priority setting literature and real health outcomes in the system, priority setting in Uganda’s health care system is hard to identify. It gives an impression that all health needs of Ugandans as understood by the government are of equal importance and urgency. The consequence of this is that there is no hope of tilting the balance of justice in favour of the most vulnerable groups of people such as the poor, women and children.

## **Conclusion**

By and large, in this chapter I have shown that Uganda is generally severely deprived of its moral entitlement to good and enabling health care. I have also argued that other than the injustice at a societal level which affects the country as a whole, there is yet another level of injustice which is even graver for those that suffer it. This deeper level of injustice is inequitable distribution of the health deprivation. The third point I have made is that the process of priority setting in the allocation of health in Uganda is not systematic enough to alleviate this latter injustice. I have argued that according to the available information about priority setting in Uganda health care, it is not easy to distinguish between the different objectives in terms of the relative importance attached to each to the others. It appears that everything that needs to be done in the system is priority. Even though some efforts are made to state priorities such as health promotion and education, disease prevention and programmes, early diagnosis and treatment, the commitment to treat all those that will seek early diagnosis, rehabilitation of health facilities among others make Uganda's health care priorities quite indeterminate. Hence, given the above listed priorities and their failure to reflect special concern for the poor, women and children, as the values for health implementation promise, it can be said that Uganda lacks clear and systematic priority setting mechanisms which need to be developed as soon as possible if the system is to function justly and efficiently. Most important to note is that the severe underfunding of the system leads to heavy reliance on the private sector – implying a 50% out-of pocket funding of health services. With extreme poverty in Uganda and very unequal income distribution, it means that this kind of financing mechanism is inequitable and disproportionately adversely affects the poor, hence inequity in health generally.

## **Chapter 2**

### **Utilitarianism in Health: the use of QALYs in Health Rationing**

#### **Introduction**

In the previous chapter I have made three points: after presenting the background to Uganda's health care system I have argued in my first point, that Uganda, as a country, is suffering health-related injustice because of severe deprivation to health entitlements. I have shown that this is due to the underfunding of the health sector. The second point I made is that, apart from the health-related injustice suffered by Uganda as a country, there is an even deeper level of this injustice within Uganda. This injustice consists in an unequal distribution of the burden of health deprivation. I have shown that this is mainly due to the inequitable financing mechanisms that Uganda relies on to finance the health system. The third point I made is that, considering the real process of priority setting that subsists in Uganda and the outcome of this process, there is no hope that justice will be done in the near future since it is still the poor, women and children that suffer it most. I indicated that as a consequence, the whole system has evidently disproportionately negatively affected the poor's access to health services and has endangered the poor household's livelihoods.

Having shown the extent and distribution of health-related injustice in Uganda, and considering that at present Uganda's efforts are not promising to make any significant positive difference, in this chapter I will analyse one of the most influential theories in philosophy and which has been widely used in the allocation of health care resources in Uganda as elsewhere in the world. By giving priority to efficiency against equity, Uganda has evidently relied on this theory to the letter. For this reason, therefore, in this chapter I will examine the theory of utilitarianism, but specifically its relevance to health resource allocation.



In this endeavour, I will make three main points. First, I will show that the QALY approach that is widely used to take decisions on health resource allocation is strictly based on the theory of utilitarianism with its maximising principles. In doing this I will explain the methods and tools used to come up the final QALYs and show that they are not value free, but actually promote utilitarian values. In the second point of this chapter I will show that there is nothing inherently wrong with the application of utilitarianism in health resource allocation. I will do this by presenting a brief justification of using utilitarian-based QALY approach to health resource allocation. I will further proceed to show, in the third point that QALY approach, though important for ascertaining efficiency in the use of health resources, misses out on other equally important moral principles and values that are supposed to be pursued in health resource allocation, especially those that aim at achieving distributive justice. But before making these three points I will start by highlighting briefly what the theory of utilitarianism is, and how it underpins the QALY approach. I will then show a very brief evolution of the QALY approach to health care rationing and then proceed to make the three central points mentioned above.

### **The Theory of Utilitarianism**

Utilitarianism in its manifestation as QALY maximisation is so far the best available theory/tool used for ascertaining efficiency in the allocation of scarce health care interventions. The theory of utilitarianism has been widely discussed and in great detail. For this reason therefore, I have no intention of repeating this discussion in this work. Instead, I will make a few remarks that are central to the theory and which are relevant for priority setting in health: that is, the basis of QALY approach to health resource allocation.

The theory of utilitarianism, also called 'utilism', is traced to Jeremy Bentham's 18<sup>th</sup> Century propagation of welfarism. In its classical statement in *An Introduction to the principles of Morals and Legislation*, "By the principle of utility is meant that principle which approves or disapproves of every action whatsoever, according to the tendency it appears to have to augment or diminish the happiness of the party whose interest is in question: or, what is the same thing in other words, to promote or to oppose that happiness" (Bentham 1781:II). However, in its modern statement and which is taken into consideration in this work, the theory of utilitarianism is based on the premise that an action is right if it produces as much or more of an increase in *aggregate utility* for all parties affected by it than any alternative action, and wrong if it does not. Hence, utilitarianism is the idea that the moral worth of an action, decision or policy is determined solely by its usefulness in maximizing aggregate utility. This is what has been the basis of the QALY approach in health.

Further, according to Jeremy Bentham's original statement of the theory of utilitarianism, it is clear that aggregation of utility is central to this theory. The idea of aggregation is derived from his contention that:

The interest of the community is one of the most general expressions that can occur in the phraseology of morals: no wonder that the meaning of it is often lost. [but] When it has a meaning, it is this: The community is a fictitious body, composed of the individual persons who are considered as constituting as it were its members. The interest of the community then is, what is it? -- the sum of the interests of the several members who compose it (Bentham 1781:iv).

These are the two most important utilitarian ideas (utility maximisation and aggregation of utility) that have shaped the QALY approach in the allocation of health resources.

## **QALY – What it is**

The acronym ‘QALY’ stands for Quality Adjusted Life Years. According to the medical dictionary, “Quality adjusted life year, [is] a year of life adjusted for its quality or its value” (MedicineNet, Inc. 1996-2010). For instance, a year in perfect health is considered equal to 1.0 QALY. The value of a year in ill health would be discounted by multiplying it with a lower weight assigned to it. For example, a year a bedridden life might have equals to 0.5 QALY (MedicineNet, Inc. 1996-2010). In this case such a year would count half a QALY. On the other hand Mo Malek defines a QALY as “an outcome measure that takes into consideration both the quantity and quality of extra life provided by a health care intervention. It is an arithmetic product of the life expectancy and the quality of the remaining years” (Mo Malek 2001). In other words, the *utility* that is gained from investing in health care intervention is usually expressed as ‘*QALYs gained*’. Hence, I will be using the concepts ‘health utility’ and ‘QALY’ interchangeably.

## **Utilitarianism’s Influence on QALY Approach**

I have just presented the meaning of the theory of utilitarianism with its two central tenets. I have also given a brief, but basic, explanation of what QALY approach is about in health resource allocation. The one point I want to make here is to call attention to the fact that the QALY approach with its major aim of health utility maximisation or cost effectiveness is a reflection of the core value of utilitarianism which is *aggregate-utility maximisation*.

It should be noted that in virtually all health interventions, the commonest question is about whether the intervention is cost effective (McGregor 2003). Indeed, this question is

increasingly asked about health interventions as the concerned health systems or financing bodies of those systems attempt to achieve the maximum health benefits from limited health care resources at their disposal. Consequently, cost-effectiveness analysis (CEA), which attempts to determine exactly how much health utility is achieved for each dollar spent, is playing a greater role in shaping most health care systems (McGregor 2003). According to Maurice McGregor, one form of cost-effectiveness analysis, cost-utility analysis, allows the comparison of different health outcomes (such as prolongation of life, prevention of blindness or relief of suffering) by measuring them all in terms of a single unit - the quality-adjusted life-year (QALY). To do this, any state of health or disability is assigned a utility on a scale ranging from 0 (immediate death) to 1 (a state of perfect health). The outcome of any health intervention, (expressed as QALYs to be gained), can then be calculated as the product of the increase in utility (from zero to one) that it may cause and the time in years over which it may be enjoyed. Following this procedure, when allocating scarce resources, those interventions that are expected to produce fewer QALYs for any given cost in comparison to those they compete with, are given a lower priority (McGregor 2003). Hence, all the QALY tools and methods presented later in this chapter are designed in such a way that the final decisions based on QALY approach would lead to the maximisation of QALYs which are a reflection of health utility. It is important also to note that QALY approach is, and should be understood as QALY maximisation. So, I will use the concepts 'QALY approach' and 'QALY maximisation' interchangeably.

### **Evolution of QALY Approach**

Although much newer than the theory of utilitarianism, QALY's philosophical parent is utilitarianism as seen above. Quality-adjusted life years approach (QALYs) has been used in the assessment of health interventions for at least three decades now. The popularity of the

QALY approach has been constantly increasing, although the debate on its theoretical underpinnings and practical moral implications is still going on.

According to Franco Sassi, the term ‘quality-adjusted life year’ (QALY) was first used in 1976 by Zeckhauser and Shepard to indicate a health outcome measurement unit that combines duration and quality of life (Franco 2006). But according to Fanshel and Bush, (2007:1021–66), among others, the underlying idea had been formally shaped in the early 1970s in the development of a ‘health status index’. It is worth noting that prior to these developments a study of the treatment of chronic renal disease by Klarman and his colleagues had used a subjective adjustment for quality of life (Klarman, Francis, Rosenthal 1968). Early applications of the health status index include one on tuberculin screening (Klarman, Francis, Rosenthal 1968) and one on screening for phenylketonuria (Bush, Chen, Patrick 1973). The QALY framework provided a basis for the development of a number of health outcome measures, including the disability-adjusted life year (DALY) in the early 1990s. The DALY is primarily a measure of disease burden (disability weights measure loss of functioning) but its use in cost-effectiveness analysis is also relatively common (Franco 2006).

### **Determining Health Utility**

As noted above, QALY approach to health care decision-making regarding resource allocation is based on utilitarianism’s central tenet of utility maximisation. For the purpose of ensuring health utility maximisation, a number of methods are used.

### **Estimating QALYs**

The estimation of QALYs is done using health preference/utility values. According to Smith and others, there are a number of elements and methods in eliciting these health preference

values. But most of these elements and methods have been said to raise methodological issues. The main and controversial element is the assignment of these preference values, sometimes known as “utilities,” to different health states. “To accomplish this, different health states need to be classified and described to a respondent, who then values them relative to one another, or an anchor point such as death” (Smith, et al 2009). Then a general index (Health Utilities Index - HUI) is created for each health state for universal and constant reference in calculating QALYs. Through research in this area a number of classification systems have been developed and these are particularly important in the case of the generic health utility measures. Some of these classification systems are the EuroQoL which uses five dimensions of quality of life, usually referred to as the EQ-5D.

Apart from the EQ-5D technique used to come up with a HUI, there are alternative approaches for eliciting the health state preference values. These are the standard gamble, the time trade-off, and the person trade-off. But in eliciting these health preference values, the key issue is that of “whose values” should be used as the source of values, - that is, between the candidates including patients, decision-makers, and the general public (Smith, et al 2009). “The weights or value “tariffs” of all the generic measures are based on surveys of the general public, although the EQ-5D also includes an assessment of self-rated health, which would be from patients when the measure is used in the context of a clinical study” (Smith, et al 2009).

There exists yet another important element in estimating the total QALYs to be gained from a given health-care intervention. This is the *aggregation* of QALYs across all the recipients. Generally, “the standard approach is to treat all QALYs gained as being equal, no matter to whom they accrue (Smith et al 2009). This is against ‘prioritarianism’ in health as we shall see later. Hence, this approach is questioned by some who argue that QALYs may have a

different weight depending on, for example, the individual's initial health state, or the state to which their health is raised" (Smith, et al 2009).

It is worthy noting that the basis of QALY and all its techniques of collecting and analysing data is the view that, when comparing health care programs, two of the most important outcome attributes are survival duration and quality of life. Hence, for purposes a health program evaluation and clinical decision analysis, it is frequently desirable to measure health outcomes as a single score that takes into account trade-offs between quality of life and survival durations. And "Following the axiom that individuals are the best judges of their own welfare, this score should also stem from individuals' preferences since ignoring these preferences in the process of decision making can result in choosing the wrong (i.e., less preferred) service" (Gale Group, Inc 2006).

### **Methods used to determine Health Preference Values**

Before proceeding to the discussion of the various method and tools used to determine the health benefits of an intervention, it is important to take note that this is not done for its own sake. Rather, as I stated earlier, it is to show that the choice of method in this case is not value-neutral. In the final analysis it will be seen that these methods promote utilitarian values.

In the effort to ascertain efficiency or cost effectiveness, an analysis (CEA) is usually carried out to predict about how much health utility will be gained by investing in a given health intervention. This process involves collecting data from the patients and the general public about how much value they attach to certain health interventions. To do this, special techniques or methods for eliciting health state preference values are used to establish how many QALYs will be gained from the proposed intervention. For this purpose special

approaches or tools are employed. The commonly cited tools are the time trade-off technique (TTO), person trade off (PTO), Standard Gamble (SG) and the EQ-5D using the Visual Analogue Scale (VAS)

### **The EuroQoL five dimensions method (EQ-5D)**

The EuroQoL five dimensions (EQ-5D) has been regarded as one of the most commonly used generic method to measure health-related quality of life (HRQoL) (Gusi, Olivares, Rajendram 2010). According to Gusi and colleagues, “The conceptual basis of the EQ-5D is the holistic view of health, which includes the medical definition, as well as the fundamental importance of independent physical, emotional and social functioning” (Gusi, Olivares, Rajendram 2010). Accordingly, the concept of health in EQ-5D encompasses both positive aspects (well-being) and negative aspects (illness). It consists of a questionnaire and an EQ-Visual Analogue Scale (VAS). The EQ-VAS is a self-rated health status using a VAS. The EQ-VAS records the subject’s perceptions of their own current overall health and can be used to monitor changes with time. The self-assessment questionnaire is a self-reported description of the subject’s current health in 5 dimensions i.e., mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The subject is asked to grade their own current level of functioning in each dimension into one of three degrees of disability (severe, moderate or none), but there has been a move to increase the levels of well-being even up to ten. Each health state can be ranked and transformed into a single score called the utility. The utility score is an expression of the Quality Adjusted Life Years (QALY) (Gusi, Olivares, Rajendram 2010).

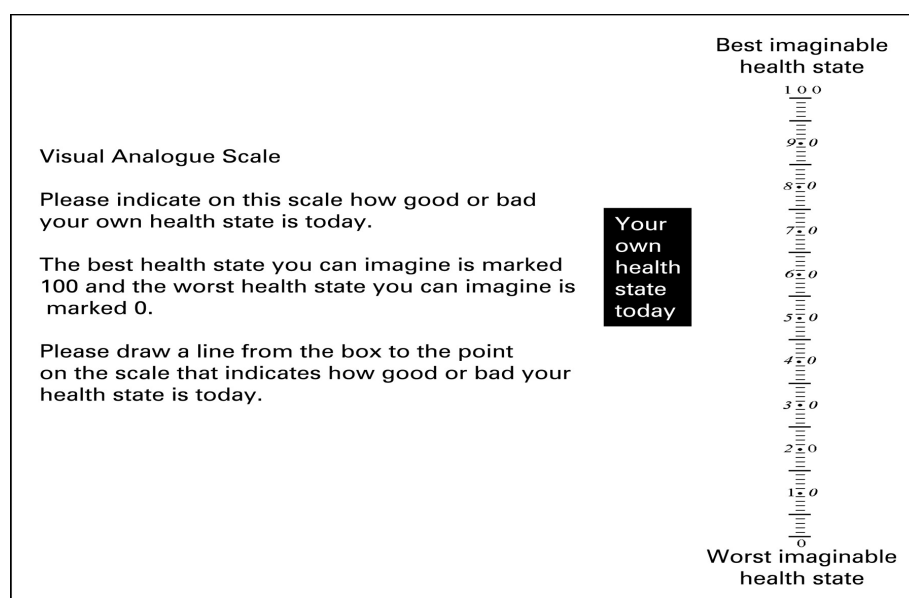
### **The Visual Analogue Scale (VAS)**

Gould D. et al, define a Visual Analogue Scale (VAS) as “a measurement instrument that tries to measure a characteristic or attitude that is believed to range across a continuum of values



and cannot easily be directly measured” (Gould, et al, 2001 ). Generally, the Visual Analogue Scale is a tool used to help a person rate the intensity of certain sensations and feelings such as pain. In health this tool is used for introspection about the respondent’s health state. For instance, the visual analogue scale for pain is a straight line labelled zero to one (sometimes one to ten). In some cases it uses qualitative descriptions of the patients’ feelings that are arranged to correspond with the numbers on the VAS. Yet, some times a plain line is used showing only two ends (No pain, at one end, and worst possible pain at the extreme end). A patient makes a point on the line that they feel matches the amount of pain they feel or use descriptive words that they feel best describes their level of pain. Some times it is used to decide the right dose of a pain-relieving medicine.

**Figure 1:** An Illustration of visual Analogue scales



*From ‘Management of Cancer Pain: Adults:’ (AHCPR 1994, Yolanda, Sculpher 2008).*

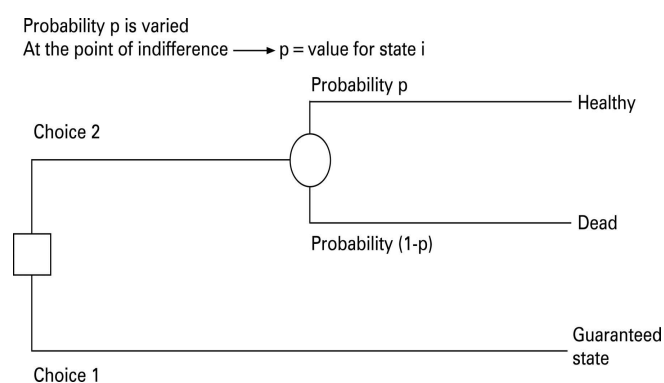
It should be noted that the visual analogue scale is used to determine the severity of ill –health. To determine the value or benefit of treatment/intervention, the patient is asked to rate their

level of health before and after treatment in order to find out how much they have been helped by the treatment received, or how much quality of life or health utility they have gained. Also, the visual analogue scale is used directly to determine the value attached to one's life in a given health state by reading directly where they say their condition falls on the scale – say 8.5.

### **The Standard Gamble technique (SG)**

It is a method used to elicit preferences to treatment decisions that will have a direct impact on the lives of the respondents. It gives a series of choices which are purported to allow the researcher to estimate the strength of the respondent's preferences regarding a specific health state under consideration. This technique is believed to help its users to understand how the respondent thinks having a particular health condition would compare to being in perfect health or being dead (Amiram 1994). According to Amiram Gafin, "The Standard Gamble (SG) technique is recommended for measurement of individuals' preferences under uncertainty. It expresses the outcome of different therapeutic choices in utility values to be used in clinical decision analysis and health program evaluation" ((Amiram 1994).

**Figure 2:** Illustration of a Standard Gamble decision tree.



*Adopted from Drummond et al (2004).*

The SG has two alternative choices: accepting treatment or no treatment. Whereas the 'no treatment' choice has the sure outcome of maintaining the health status quo, the treatment option has two probabilities ( $P$  and  $1-P$  – in the figure above). Outcome  $P$  would lead to health after treatment, while  $1-P$  would lead to death from the same treatment - say an operation. Normally, the outcomes of treatment are assigned probabilities of occurrence – say  $P = 0.6$  and  $1-P = 0.4$ . The choice made by the patient bearing in mind the probability of death indicates how much importance they attach to their lives without treatment. If patients make a choice for treatment when the probability of death is high, then it means that they are living with severest pain worth risking their lives with treatment. In this process the probabilities keep on being varied up to a point when the patient feels indifferent to whichever choice that is taken of the two. The point at which they are indifferent between the two choices is what is taken to be the value of the current health state.

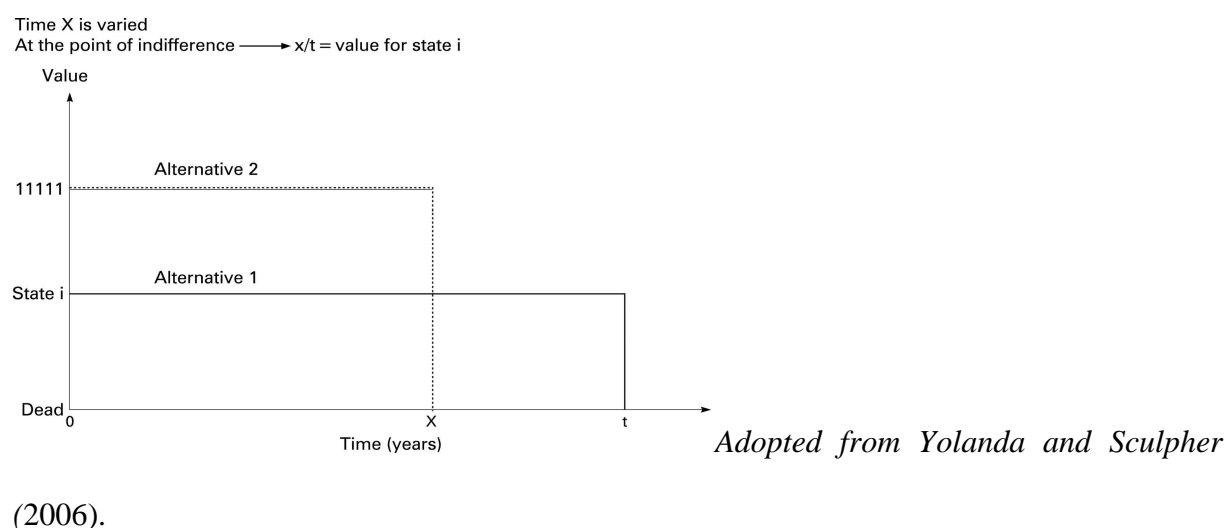
### **Time Trade-Off**

Time trade-off is a tool used in health economics to help determine the quality of life of a patient or group of patients. Using this technique, the individual will be presented with a set of directions such as:

Imagine that you are told that you have 10 years left to live. In connection with this you are also told that you can choose to live these 10 years in your current health state or that you can choose to give up some life years to live for a shorter period in full health. Indicate with a cross on the line the number of years in full health that you think is of equal value to 10 years in your current health state (Burstrom, Johannesson, Diderichsen 2006:359–370).

In other words the basic question asked in time-trade-off technique is ‘In your current health state, how much of your remaining life expectancy would you give up so as to live in perfect health? In this case the health utility of an intervention is the sacrifice they are willing to make. In both TTO and SG methods of estimating the utility of a health intervention, the respondents are expected to make a sacrifice of part of their remaining life years or risk the whole of their remaining life expectancy for the sake of gaining perfect health from an intervention. The utility of the intervention is then normally estimated in terms of how much of their remaining life expectancy the respondents are willing to forego to be in perfect health.

**Figure 3:** Illustration of time trade-off



According to the above illustration one has alternative 1 of living up to ‘t’ years in a state of poor health - ‘health state alternative i’. But the patient, because of the value they attach to an intervention that would restore their perfect health may choose alternative 2 to give up ‘x-t’ years (in the figure) in order to gain a top-up on their health (from health state i to 11111), hence live in a better health state 11111. Hence, the value of their life without treatment would be represented by the following equation:

Let the value of perfect health = 1

Hence, the value of health without treatment =  $1 - ((t - x)/t)$ .

Following this equation it means that if a person's remaining life expectancy was 10 years (between '0' and 't' in the figure above), and assuming that 'x' stands at the sixth point, it would mean that the value a person attaches to their life without treatment is 0.6. Differently put, to such a patient, 10 years in their current ill-health is equivalent to 6 years in perfect health, or 6 QALYs. Hence, an intervention that would restore their perfect functioning would be valued at 4 QALYs.

### **The person Trade-off Technique (PTO)**

One method proposed to determine the value society attaches to certain health benefits is what has been called the 'Equivalence of Numbers' or Person Trade-Off technique (Pinto 1997:71–81). According to Richardson, in using this method respondents are normally asked questions such as: "if there are  $x$  people in adverse health situation A and  $y$  people in adverse health situation B, and if you can only help (cure) one group, which group would you choose?" (Richardson 1994:39). One of the numbers  $x$  or  $y$  can be varied until the subject finds the two groups equivalent in terms of needing or deserving help. The undesirability (disutility) of situation B is  $x/y$  times as great as that of situation A' (Pinto 1997:71-81). PTO has been said to be advantageous because it asks the right question. According to Pinto "If the values of the health states were used to make trade-offs between people, the best thing to do would be to ask that question directly. "Better than standard gamble would be equivalence of numbers, whereby trade-offs between different people's lives are clear. Best of all would be explicit QALY bargain questions. ... Without some such explicit link between the questions used to

establish quality indices and the allocations generated by QALYs, QALYs will remain persistently suspicious” (Pinto1997:71-81).

Like the name suggests, person trade-off means exchanging one person’s life (or a group of people) or improvement in health for another person’s upon a conviction that the life or health of the person lost or denied treatment is of less social value than of the one whose life is saved or treatment given. According to Williams, Mulley, Nord, allocating scarce resources in health care essentially means dealing with person trade-offs (Mulley 1989, Nord 1992). To Nord, “the person trade-off technique is a way of estimating the social value of different healthcare interventions. It basically consists in asking people how many outcomes of one kind they consider equivalent in social value to ‘X’ outcomes of another kind”(Nord 1994). For instance, if a given treatment ‘A’ is twice the cost of treatment ‘B’, then it is advisable to give priority to treating two patients who need treatment ‘B’ at the cost of the patient that needs treatment ‘A’. In other words, the life or good health of one person will have been traded-off or exchanged or sacrificed for that of the other two patients. This is what essentially lies at the heart of attempting to maximise health utility from the available resources using QALY approach. A practical example of person trade-off is one that faced the Oregon Health Commission of having to choose between spending health resources on 100 patients that needed tooth capping, or on one person that needed renal dialysis, whereby in both choices the costs would be the same (Brock, Wikler 2005).

### **Calculation of final QALYs:**

Generally, according to most literature on QALYs, “The technical term for respondents’ preferences is utility. Utility values can be gathered by asking people about their preferences for various health states” (Mo Malek 2001 ), using methods and tools shown above. And once

these utility values are obtained, the calculation of QALY proceeds by multiplying the utility value of a health state by the length of time spent in that health state. Hence, “one year of perfect health (utility value of 1) equals one QALY, which is a product of one and one. Similarly, two years spent in a health state with a utility value of 0.75 equals 1.5 QALYs, or 1.5 years of perfect health” (Mo Malek 2001 ) which is also obtained by multiplying 0.75 by 2.

### **Determining cost effectiveness using QALYs**

The essence of determining cost effectiveness is to ascertain whether the health care intervention under consideration will maximise health benefits. This is the major aim of this utilitarian-based QALY approach to health rationing. A cost effective health intervention is normally one that makes it possible to get the highest aggregate health utility possible using a fixed budget.

Calculating QALYs per se does not tell whether or not the intervention under consideration will lead to health benefit maximisation. Rather, the cost effectiveness of health care programmes is determined by calculating cost per QALY. Utility values, and therefore QALYs, are calculated for any health care intervention where there is a measure of utility for health states following the intervention. If the costs associated with the intervention can also be calculated, then a cost utility value can be derived (McGregor 2003). This is expressed in units of cost per QALY and provides an estimate of how much it would cost to provide one year of perfect health (that is, one QALY) following that intervention. In other words, these estimates represent a measure of the value for money that the intervention provides. Given a number of competing interventions, priority is then given to the intervention that will lead to the acquisition of the most QALYs using the same amount of resources.

## **The Moral Status of QALYs in Health Rationing**

I have so far made a point about how QALY is actually based on utilitarianism's maximising principles. I have done this through the discussion of the main methods and tools used to ensure that maximum health utility is gained from an intervention. The point I want to make below is to argue that there is nothing inherently wrong with health benefit maximisation. I will do this very briefly by showing that there is a valid moral justification of using the QALY approach in the allocation of scarce health resources and later show the 'fairness gaps' left behind by total reliance on QALY approach in health resource allocation.

### **Justification of using QALYs**

The application of the theory of utilitarianism in health resources allocation has been vehemently criticised especially for its alleged blindness to distributive justice. However, even though this may be true (as I will show in my third point immediately after this one), limited efforts, if any, have been made to show a logically valid moral justification of using QALY-based utilitarianism in the allocation of scarce health interventions at the disposal of the public sector. What may be considered to be the usefulness or the positive side of using QALY as a tool of health policy analysis is summarised in the following argument:

- The state or government has the primary moral duty of *stewardship* in managing the country's health care resources on behalf of its populace.
- The concept of stewardship presupposes the task of ensuring prudence or rational use of national resources.
- Rational use of resources (economic rationalism) implies achieving the possible maximum gains from the available resources – cost effectiveness/efficiency.
- Utilitarian-based QALY approach is the best tool available so far used to ascertain efficiency in the use of health resources.



- Therefore, the state/government has a moral duty of, and is morally justified to rely on the use of QALYs to ascertain efficiency in the use of health care resources.

If the above argument should be qualified as valid, then from moral point of view, the government is morally justified to rely on QALY approach in the decisions regarding priority setting between competing health care interventions. Therefore, “cost-effectiveness is not merely an economic concern, because improving people’s health and well-being is a moral concern, and an allocation of resources that is not cost-effective produces fewer benefits [hence weak moral legitimacy] than would have been possible with a different allocation” (Brock, Wikler 2005). Further, “cost effective analysis (CEA) identifies one important ethical criterion in evaluating health care interventions – producing the most benefits possible for individuals served by those interventions ...” (Brock, Wikler 2005). Hence, the moral justification of using QALYs is the fact that the government has a stringent duty of ensuring efficient use of its resources and producing as more health benefits as possible for its population. However, another question, as will be seen below, is whether it should matter how these health benefits are distributed or not. According to QALYs approach as it stands now, it does not matter how these benefits are distributed.

Other than the above moral justification, it is further claimed that the QALY’s benefit for health-care evaluation is its applicability to “all individuals and all diseases” and can therefore be used to compare interventions across diseases and programs (Smith et al 2009). It is thus particularly important to outcomes researchers as they attempt to evaluate the efficacy and cost of various health-care interventions and to health-care decision makers as they weigh implementation or purchase of healthcare technologies, including diagnostics, devices, and medications programs (Smith et al 2009). This QALY analysis has been used by some health-care systems, such as the National Institute for Health and Clinical Excellence (NICE) of the

British National Health Service (NHS) to determine health-care priorities; and QALYs are also used in population health, to measure and compare the health of a community (Smith et al 2009).

But if the use of QALYs in the allocation of health resources is justified as shown in the above argument, where do the doubts about its use come from? This is the question I am set to answer in my third point of this chapter, below.

### **Doubts about the Moral status of QALY**

The answer to the question about the sources of doubt about reliance on QALY posed above has nothing to do with its logical and moral validity as the argument above shows. Rather, the ethical doubts about QALY are from the point of view of the moral implications of its level of technical accuracy and objectivity, on one hand; and its theoretical underpinning; that is, a realisation that other than utilitarianism, there are other strongly compelling moral principles in the allocation of health care resources that ought to be considered, yet they run counter to principles that underlie QALY approach. This is the idea that has been a basis of the various criticisms by various health ethicists and has been the motivation behind McGregor's caution: "*Cost-Utility analysis: Use QALYs only with great caution*" (McGregor 2003).

### **Doubt from Technicality**

The ability to compare directly the dollar cost of different health outcomes is attractive to the decision-maker. Although this is the case, caution should be taken that the use of QALY approach for this purpose has severe limitations and these must be widely understood, above all by the decision-makers who use QALYs (McGregor 2003).

Those that are sceptical about the use of QALYs in health resource allocation decisions insist that it must be objective and relevant such that it is applicable to the biggest percentage of the population affected by the policy in question. However, in practice it is always hard and often impossible to be sure that these conditions are met by QALY approach (McGregor 2003). One example that has been used to corroborate this claim is from the study of the drug called sildenafil which was carried out explicitly to help insurers decide whether they should cover the cost of this drug. This study was carried out by Smith and Roberts (2000:933-7).

Sildenafil is a drug taken shortly before sexual intercourse to correct erectile dysfunction. However, this study was carried out because there was uncertainty as to whether insuring agencies and public health care should cover its cost. The study in question concluded that the cost-effectiveness (direct medical costs only) of taking sildenafil five times per month would be US\$11 230 per QALY, and that this "compares favourably with other medical conditions, costing less than renal dialysis, cholesterol lowering medication, and coronary artery bypass grafting" (Smith, Roberts 2000). Following the above example, QALY's relevance and objectivity has been seriously questioned.

As noted above, the QALYs measured in the study should be applicable or relevant to the population that will be influenced by the policy in question. But the source of contention is that in the process of determining QALYs, utility estimates vary according to who is making the estimate, (Drummond, McGuire A 2001), hence severely limiting its relevance to the rest of the population. For instance, the increase in utility attributed to sildenafil in that study was based on a paper by Volk and colleagues (Volk, Cantor, Spann 1996) who questioned 10 healthy men whose average age was 56 years, about the importance they attached to erectile function. Using the time trade-off technique, these men estimated that, compared with perfect

health, the reduction of utility they would experience with impotence would be 0.26 (i.e., they would forfeit 26% of their expected healthy life to avoid impotence!). However, when this was estimated by their wives, the result was remarkably different: 0.02 (they were willing to give up only 2% of their healthy life). Further, from responses of cancer patients on the utility they attach to a life lived in impotence, physicians who treat prostate cancer have estimated the loss of utility attributable to impotence to be 0.05 (Fleming, Wasson, Albertsen, Barry Wennberg 1993) and 0.15 (Klarman, Francis, Rosenthal 1968). Hence, following these radically different utility values attached to the same health condition by different groups of people, there is not yet unanimity as to whose viewpoints should be used when making societal policy decisions (McGregor 2003). This example illustrates the difficulty in achieving objectivity and universal relevance of decisions to treat certain health conditions because, in this case, how important it is to treat this condition will depend on which (whose) utility estimates one uses. In this example the policy based on the QALY approach would be relevant only to men and not women. This domination of one group by another is arbitrary and out of consonant with the concept of individual autonomy of each candidate for health care, and is a moral evil. Even though it may be impossible to respect every individual's autonomy in the allocation of health resources, but the wider the relevance of the allocation decision the better.

### **Doubt from Theoretical Underpinning**

The most debatable issue about the use of QALY approach in analysing the cost effectiveness of any health intervention is its theoretical underpinning. Hence, the ethical implications involved in QALY-based Cost-Effective Analysis (CEA) require closer attention. As shown earlier, utilitarianism, a very controversial moral theory, is CEA's philosophical parent. Beauchamp and Childress have for example argued that, implicit in QALY-based CEA is the

idea that health maximisation is the only relevant objective of health services (Beauchamp, Childress 2001). However, some non-health benefits or utilities of health services also contribute to quality of life. Hence, the problem is that QALY-based CEA attaches utility only to selected outcomes while neglecting values such as how care is provided, and how it is distributed (whether universal access is provided) (Beauchamp, Childress 2001)

Whereas everybody agrees that utility, and/or health and the utility therein, is a good thing, and that all other things being equal, more utility is better than less utility, many critics of utilitarianism attack it for its promotion of utility above all other human goals – in this case distributive justice. Hence, as I have argued earlier, there is nothing intrinsically morally wrong with maximising utility, no matter how the concept is defined. Whatever a society counts as utility is worthy of pursuit and maximising. But in general or in particular, when applied to QALY as a basis of health resource allocation, health utility maximisation faces a number of challenges which its critics demand that they be addressed in health policy regarding resource allocation. Below, I will briefly discuss some of these challenges, one a time.

### ***QALYs and the value of health***

One of the questionable issues embedded in the QALY approach is the perception of the value of health held by its advocates. It is this perception that is the sole guiding principle of cost effective analysis and QALY in general. This perception is that health is an end in itself or, that health has an intrinsic value. This is one common ground that the opponents of QALY approach base on to cast doubt on the approach. Roger Crisp, to begin with, argues that the problem with QALY approach, with its basis in utilitarianism, makes a mistake of looking at health as an end in itself. It is normally tempting to think that, if health care is to promote well

being, then health care budgets should be spent so as to maximise the well being, or expected well being of a population. This view would involve injustice. Instead, the reason we spend money on health care or what we are said to be purchasing through buying drugs, surgery and so on, is not health in itself. The common view in the QALY/utilitarian approach to health care policy analysis is that, health budgets should be spent with the sole aim of maximising the overall health of the population. This is what mistakes health for an ultimate good, since the good of health is only derivative or instrumental, to the extent that promotion of the possible maximum health in the population can not in itself justify expenditure on health care. (Beauchamp, Childress 2001). The final or ultimate good, to which health serves as a means, is well being or welfare – that which makes life worth living, or better, or for the person living that life. This is the feeling of justice with which people feel are being treated. According to Aristotle, the ultimate good to which health is a means, is a virtuous life; and justice is a virtue.

It should be noted that the critics of QALY maximisation as a basis for rationing health resources are not opposed to maximising benefits from the available resources as such. Rather, the source of doubts about the use of QALYs is its extremism; that is, saying that health maximisation is or should be the sole aim of spending money on health care without taking into account distributional issues. Hence, the concern ought to be how to incorporate non-health gains as opposed to gains only in terms of preventive and curative interventions into the health system and the policy that guides it. One way, for instance, of incorporating non-health gains as one of the aims of a health system is to mitigate the consequences of total reliance on QALYs with concerns of distributive justice. In this way the utility gained from health interventions would be of both health and non-health utility which is generally believed to be of value to society.

Peter Singer and others argue that QALY approach as it stands now, leads to unfair recommendation about how the state should spend its health care resources. Generally, higher utility can be achieved by giving priority to the poor and the worst off even if the value they attach to their health is low and their prognosis is poor. The reason behind this argument is that utility in general is not to be found in health but in the way people perceive the extent of fairness, concern and compassion with which they are being treated. Hence:

There is more to overall utility than health-related QALYs, and it is plausible to suppose that tilting the balance of health care towards the more disadvantaged members of society will reinforce feelings of concern and sympathy, and lead to a more compassionate society. This in turn may be a society with more community feeling and therefore one that provides a higher level of general welfare than a less compassionate society (Singer, McKie, et al. 1995).

### ***Life Years versus Lives***

The concept of 'Quality Adjusted Life Years', as defined earlier, implies that it is not automatic that all of one's years of life are treated as 'quality-adjusted life years. Rather, the number of QALYs a person is said to possess depends on the QoL they will enjoy after a health intervention. For instance, if one's QoL is to be diminished by a certain permanent disability after treatment, then, all other things considered, they will gain fewer QALYs than another person with out any disability. And following the recommendation made based on the QALY approach the person with disability should be ruled out as a candidate to receive health care, if there are no extra resources available for them. This is the logical implication of the move to maximise life years (QALYs).

Accordingly, QALYs attach more value to life years than on the number of human lives to be saved by an intervention. For instance, all things considered, QALY would give priority to a 15 year old youth who is likely to live up to the age of 80, against 6 people whose lives would be extended by 10 years each. The reason for this is obvious – giving priority to the former would lead to the acquisition of 5 more QALYs. Put differently, given two equal groups of patients A and B with a similar and curable condition, but patients in group B have some permanent disabilities not target by the intervention under consideration, then QALYs would give priority to group A, all other things being equal more QALYs would be gained from group A – the concern here is not that the number of lives to be saved is the same, but it is that the number of QALYs to be gained is in favour of the group without any disability.

To illustrate this point, the QALY approach in the above way puts the permanently disabled patient at a disadvantage. This applies in the following hypothetical case:

Consider the out come of a QALY analysis to guide decision about two patients with *retinitis pigmentosa* of the same severity. But all other things being equal, the difference between these two patients being that one patient – say ‘A’ has a permanent disability that would give him about 0.8 QoL after a successful retinal implant; and on the other hand patient ‘B’ has no disability at all and would enjoy a QoL equal to 1.0. If both patients had equal life expectancy remainder – say 20 years, it then follows that patient ‘A’ would gain 16 QALYs while patient ‘B’ would gain 20 QALYs. For the need to maximise life years gained, priority would be given to patient ‘B’. This is what Singer and others mean when they talk about double jeopardy for the permanently disabled; that because of living a permanent ‘wheelchair life’ this patient should miss a life-improving intervention because there is someone that would lead a higher quality of life than him (Singer, McKie et al 1995). This is a kin to literally saying that,



... Therefore, take the talent from him and give it to the one who has ten. For the one who has will be given more *and he will have more than enough*. But the one who does not have, even what he has will be taken from him. And throw that worthless slave into the outer darkness, where there will be weeping and gnashing of teeth” (Matthew 25:28 – 30).

In the health ethics discourse, Harris John raises a complaint against this way of doing things, in his *double Jeopardy* argument:

‘QALYs dictate that because an individual is unfortunate, because she has once become a victim of disaster, we are required to visit upon her a second and perhaps graver misfortune. The first disaster leaves her with a poor quality of life and QALYs then require that in virtue of this she be ruled out as a candidate for life-saving treatment, or at best, that she be given little or no chance of benefiting from what little amelioration her condition admits of’ (Harris 1987:17).

Hence, from the above it can be seen that the use of the Quality Adjusted Life-Years (QALY) as a basis of allocation of health care resources is morally weak. This is for the reason that it gives a lower value to preserving the lives of people with a permanent disability or illness than to preserving the lives of those who are healthy and not disabled. The reason for this is that the quality of life of those with illness or disability is ranked, on the QALY scale, below that of someone without a disability or illness. Hence, following this line of analysis, we can, other things being equal, gain more QALYs by saving the lives of those without a permanent disability or illness than by saving the lives of those who are disadvantaged in these ways. This is injustice because it constitutes a double jeopardy for the already disadvantaged people

by worsening their deprivation to good health. “Not only do they suffer from the disability or illness, but because of it, a low priority is given to forms of health care that can preserve their lives. This is unjust or unfair”(Singer, McKie et al 1995). Further, it is for this reason that Harris John believes that, “QALYs are a life-threatening device” because they suggest that life years rather than individual lives are valuable (Harris 1997:17).

### ***Priority to the worst off compromised***

The worst off in health care, though defined in many different ways, are basically understood to be those with urgent health needs – whichever way the concept of urgency may be defined. But many would agree that the severely ill, the poor and all those who are socially disadvantaged in ways that directly affect their health have the greatest need.<sup>4</sup> One of the weaknesses of utilitarianism when applied to the allocation of health resources is that its principles compromise justice in health care by denying priority to the worst off. This is against the moral essence of social cooperation. It should be remembered that the overarching goal of social cooperation, and therefore social policy, is to ensure justice and fairness in society – defend the minority, the weak and the disadvantaged – the same reason behind Thomas Hobbes’ idea of ‘*the social contract*’ - and an end to the state of nature (Hobbes 1660:XIV). Further, it is reasonable that the guardians of a society act in such a way that they get the best and the most from the resources available to them. Although this is the case, they must care about how this utility or happiness is distributed. The argument against QALY approach is therefore that it does not respond appropriately to the issue of urgency or emergency in health care. Urgency in health care is expected to lead to priority to the patients with very severely painful and life-threatening illnesses as long as their prognoses are good.

---

<sup>4</sup> I will extend this argument in the next chapter (3) under ‘prioritarianism’ as one of the proposed principle for allocating health resources.

Nord argues that the assumption of "distributive neutrality" that underlies the QALY approach frequently violates societal concerns for fairness in the allocation of health care resources. For example, society does not consider a unit of health gained by a severely ill individual to be of equal value to a unit of health gained by an individual who is less severely ill (Nord 1999). McGregor adds that, though as yet unstudied, a QALY gained through correction of erectile dysfunction by an otherwise healthy individual would probably not be considered equivalent to a QALY gained through life-prolonging dialysis by an individual about to die from renal failure (McGregor 2005).

### ***QALY is anti-egalitarianism***

Further, those that care about equality of opportunity in health care have raised questions as to whether CEA is egalitarian; or whether policy based on cost effective analysis guarantees health equity. Even though the theory of egalitarianism has itself been subject to the levelling down objection (Holtug 1998), it is intended to achieve distributive justice in health. The truth about the QALY approach is that life years matter more than the number of lives saved, as argued above. For this reason, those with better prognoses are always favoured at the expense of those in the opposite state. In other words, the better-off are more entitled to health services than the worst-off. There can not be said to be equal treatment in this case. It is because of this feature of QALY-based CEA that makes it favour Life Years over individual lives (Hotlug 1998). In practice, proponents of QALY hold that each healthy life year is equally valuable for everyone; that a QALY is a QALY regardless of who possesses it. This argument is a very clear testimony that QALYs are indifferent to distributive justice. Instead, as opposed to this argument it should matter so much how fairly the QALYs are distributed. Hence, from the methods and tools of analysis used to come up with the final figure of

QALYs to be gained, the answer is no – QALY qua QALY is neither egalitarian nor does it lead to equity in access to health care.

### *Aggregation of health output*

The aggregation problem in health consists in the dilemma of whether to provide small benefits to many people or large benefits to a few. The issue of aggregation is pertinent in health discourse because of the need to balance two most important aims of health systems. These are efficiency and equity. So the need to balance the two makes it necessary to try to resolve the dilemma posed by the aggregation problem.

One serious criticism that has been levelled against QALY approach as a basis to decide on the allocation of scarce health care resources is related to problems with aggregation of health output, a principle that lies at the heart of utilitarianism. In health care, QALY usually aims at the aggregate of health benefits or the total sum of the health benefits obtained from any healthcare intervention. Aggregation in health is indifferent to whichever decision is taken as long as the maximum QALYs are obtained from that budget. The critics of QALY approach from the point of aggregation claim that it is utilitarian and it is interested in the overall health outcome of the system without caring about how fairly these benefits are distributed. Further, since aggregation is more interested in the highest QALYs possible, it does not respond to the issue of urgency. Urgency sometimes requires giving priority to those with severe pain and facing the immediate threat of death if left un-helped, even though doing this may result in comparatively fewer QALYs.

On this subject (aggregation), Lubbe's opinion is that "under conditions of scarcity, more of what is good seems better than less. ... [but] I can think of no ethical basis for additive utility

aggregation if such aggregation is not fair” (Lube 2009:2). Further claims of justice must not be weighed with other objectives, but must be redefined, not weighed, if there actually are legitimate objectives that are not compatible with satisfying them(Lube 2009:2).

### ***Defending QALY's Aggregation***

There has been an attempt to show that aggregation in QALY calculations addresses the issue of urgency – that is, of priority to the worst off (Nord, Pinto, Richardson, Menzel, and Ubel 1999). Apparently, Nord and colleagues claim that aggregation is compatible with fairness in health care resource allocation. They claim that it is possible to aggregate QALYs in an egalitarian way. They argue that:

The egalitarian way of aggregating health benefits is the following. When we aggregate health benefits, we assign a greater weight to the lower level of health condition, and add up the weighted health benefits. In practice there would be several ways to do this. Here is one way. First, when we estimate the health related quality of life, we assign more weight to the serious disease. Second, we multiply by the number of years. Third, we add up the weighted QALYs, and choose the plan that maximises the weighted QALYs (Hiroes 2009:7).

Their formula, they claim - and as matter of fact, “gives a greater moral importance to more serious illness, and hence meets the demand of urgency...” (Hiroes 2009:8).

The above approach sounds ‘liberative’ to the QALY approach. It provides a promising step towards fairness in health care without losing a score on efficiency. On the contrary, however, this approach still does not address the ethical controversy that surrounds the concept of *Quality-Adjusted Life Years*: That is, is it morally admissible to hold as a general rule that,

people with any sort of disability are less human than those without; such that, all other things considered, the former should always be discriminated against in allocation of scarce resources in favour of the latter? In this case, whereas this new approach does well to give priority to the worse off by assigning serious illness a greater weight, this weight does not extend to the years of life saved, which he admits are not weighed. The reason for not weighing these years is that, “This is because I believe that the notion of urgency is concerned with how we react to a person’s serious situation at a given time (Hiroes 2009:8).” Hence, it is not clear how this new approach would proceed in a case as one below.

Imagine person ‘A’ with a certain permanent disability, develops a very severely painful but treatable illness, such that without treatment her quality of life will be about 0.55 whereas after treatment she will live quality of life weighing 0.75. Another person, ‘B’, without any disability but with a less serious illness as that of ‘A’, and will live in 0.8 quality of life without treatment but can improve this to perfect health (1.0 weight) after treatment. In both cases no immediate threat of death is posed by the illness except life-long suffering. In this case, urgency is determined by the severity of one’s condition (pain or the degree of suffering). Hence, A’s need will be more urgent than B’s. And let us also assume that with or without treatment both patients have equal life expectancy remainder – say 20years. This automatically means, following the concept of ‘quality-adjusted life years’ that ‘B’ will gain 20 QALYs while ‘A’ will gain 15 QALYs. The reason why QALY approach fails to accommodate the demand of urgency contrary to what Hiroes et al claim above, is that the greater importance attached to A’s condition does not extend to her years of life after treatment because of her permanent disability. Hence, her QALYs gained will remain 15 against B’s 20. Since the concern is still the maximum *Quality adjusted life years*, it is not clear how the weight attached to A’s condition will affect how many QALYs she will gain.

So, if the decision on who should receive priority is to be based on the final number of QALYs to be gained, it would still be to the disadvantage of A, yet she is living in the most severe pain (urgency). It would be very unfair to give preference to B with less severe pain for the sake of gaining 20 QALYs at the expense of A, who is in severe pain but would only gain 15 QALYs.

### **Social Aversion for QALY Maximisation: Empirical Evidence**

In their survey of the attitudes of Australians to the distribution of health care, Nord and his colleagues report that they found that many respondents were ready to depart from QALY maximisation in order to avoid expressing a priority for the treatment of some patients over others. They attribute this kind of attitude towards QALY to people's concern for the effects that a direct maximisation approach has on the kind of society we are. For example,

When asked whether, among patients who are suffering equally, some priority should be given to those who will be helped most from treatment, only about half (53 per cent) of those answering favoured doing so; the remainder thought that those who could become a little better should have the same priority as those who could become much better. Even more striking responses were received to a hypothetical choice between patients who can be helped at low cost and those who are equally ill, but can only be helped at high cost. Overwhelmingly, 81 per cent of respondents favoured equal treatment irrespective of cost, except when the costs are extremely high. Even when presented with a hypothetical example showing that giving priority to low-cost patients would allow more patients to be treated overall, most respondents did not choose to maximise health benefits (Nord, et al 1995).

### **Conclusion**

Generally, according to the QALY approach, a cost-per-QALY ratio indicates the cost-effectiveness of an intervention. As such, the ratio is a measure of efficiency, rather than of “fairness.”<sup>5</sup> There is a great concern about the challenges raised by the failure of QALYs to account for distributive concerns, e.g., the relative priority given to individuals of different levels of current health, and/or different capacity to benefit in terms of life expectancy or health-related quality of life, as Drummond et al exemplify (Drummond, et al 2001). In decisions about resource allocation across patient groups, concerns for fairness will count alongside concerns for efficiency in the production of health. The reason for this is that such concerns may cause social resource allocation preferences to deviate considerably from the ranking that consideration of costs per QALY would suggest. These concerns have been raised internationally in all settings where cost-effectiveness analysis has been studied and/or applied (Drummond et al 2001). Therefore, this makes it morally unnecessary to base health resource allocation solely on utilitarian principles, hence there is need to consider other morally compelling values to guide decisions on health care rationing. I will explore some of these principles in the next chapter, and finally gauge whether these, together with QALY can be enough in ensuring health equity in Uganda.

---

<sup>5</sup> This idea is shared by Weyma Lube who argues that there is a good reason for accepting that maximising overall health benefit [in itself] is not an ethical objective (Lube 2009:2).



## Chapter 3

### Criteria for Rationing Health Resources: Ethical Dilemmas

#### Introduction

In the preceding chapter I have discussed the major and commonly used theory – *utilitarianism*, and its consequent approach to priority setting in allocation of health care resources. I have argued that the philosophical underpinning of the QALY approach is really the theory of utilitarianism, that is, utility maximisation, although in this context it is understood as health utility or QALY maximisation. I have argued that the application of the utilitarian values in allocation of resources especially in extreme scarcity is not inherently morally wrong. I have further argued that whereas utilitarianism in health is not unethical in itself, for purposes of achieving equity it is not sufficient simply to base allocation decisions on utilitarianism alone. And for this reason, the QALY approach needs to be supplemented by taking care of additional moral concerns that are discussed in this chapter.

In this chapter I argue that other than health benefit maximisation there are other highly compelling moral principles advanced that ought to guide the allocation of the scarce health resources. But whereas all these principles, or at least most of them, seem intuitively morally convincing when treated in isolation from others, none of them is strong enough on its own to guide the equitable allocation of health resources. The second argument is that, having noted the inefficiency of each single principle on its own, a combination of principles has been suggested in what is called the *Complete Lives System*. I argue that even though this combination avoids many dilemmas, it is not a perfect solution to all the dilemmas in the allocation of health interventions. In the third point I explore yet another suggestion that has been made to guide the allocation of health resources – *the Fair Procedures* suggestion. I argue that, as opposed to the ‘Fair Procedures’ suggestion’s claims of making unnecessary a

discussion on the substantive ethical principles of allocation, it is impossible to talk about equitable allocation of scarce resources without making reference to these controversial substantive ethical principles. I will present this chapter in three parts corresponding to the three points I have mentioned above. But before that, for purposes of emphasis, I will reiterate some general remarks about the on-going discussion as background to this chapter.

## **Background**

As noted earlier, one of the greatest challenges facing the health sector globally and domestically is scarcity of resources to meet all the medical and non-medical health needs of all concerned populations. As a result, the latest and stringent concern in the provision of health care services, whether domestically or internationally, is fairness in allocating these scarce resources, and having to balance this with efficiency. Health care systems are normally evaluated in relation to how best they meet their most important aims and objectives. In this case, the most important aims of health care provision are justice/fairness, on one hand, and efficiency on the other. Health care systems and health care providers have found themselves in dilemmas, especially when these two important aims are in conflict.

Generally, the aims of health care systems are not just limited to efficiency and fair distribution, even though these are accepted to be the most robust ones. Other aims and objectives of health systems include Health, quality, responsiveness and trust. Of these other aims, Mechanic has vehemently argued for the importance of ‘trust’ in a health system especially bearing in mind that with the existing resource constraints amidst endless health needs it is impossible to meet everybody’s needs (Mechanic 1995).

According to Brock and Wikler, it is now widely recognized that Cost Effective Analysis (CEA) or the QALY approach alone is not a satisfactory guide to resource allocation in all cases. There has been a realisation that CEA, as customarily formulated to measure the sum of costs and benefits from any health care intervention, largely ignores the pattern of their distribution across the affected population. “In some cases, the resulting allocation will strike most observers as unfair. Health resource allocators need to take distributional issues into account along with cost-effectiveness (Brock, Wikler 2005).

For the purpose of ensuring equity in health a number of moral principles have been proposed and widely discussed for consideration when setting priorities in health care rationing. Even though most of these are valid, reflection on the need for equity in health suggests that some moral principles would command more moral weight than others, but still there is not yet agreement on which ones should count more than others.

## **Part I**

### **Substantive Moral Principles for Health Rationing**

As I noted earlier, these principles are necessitated by the fact that, the theory of utilitarianism with its consequent QALY approach in the allocation of health resources is blind to concerns of distributive justice. Hence, in an effort to take care of these concerns without missing out on efficiency, a number of ethical principles have been suggested and highly debated. They include the principle of ‘treating people equally’, prioritarianism, ‘saving most lives’ versus ‘life years’ instrumentalist views, allocation by need and ‘fair chances and best outcomes’. Some of these principles seem to repeat utilitarian values but in this case they seek to incorporate concerns of distributive justice into health utility maximisation. I will examine

one at a time, below. In this part I will rely mainly on the overview by Persad and his colleagues who seem to have analysed these principles exhaustively.

### **Treating people equally**

According to the principle of ‘treating people equally’, just allocation of scarce interventions consists in giving equal probability of getting or not getting such interventions to those who are equally entitled to them. In congruence with John Rawls’ view on how indivisible goods ought to be fairly distributed (Rawls 1999), many scarce medical interventions, such as organ transplants, are indivisible. For indivisible goods, benefiting people equally entails providing equal chances at the scarce intervention—equality of opportunity, rather than equal amounts of it (Persad, et al 2009: 423-431). But whereas it may be agreed that treating people equally is fair, it is controversial what exactly it means to treat people equally. The two options that are thought to lead to equal treatment of two individuals or groups of people are either allocation by ‘lottery’ and/or allocation on the basis of ‘first-come first served’.

### ***Allocation by Lottery***

One of the criteria believed to ensure equal chances of receiving care when resources are limited, is using lottery. This is mainly recommended in deciding between two individuals or groups that do not exhibit marked differences in their health needs. The arguments appealed to in favour of this criterion are that: “Equal moral status supports an equal claim to scarce resources. Even among only roughly equal candidates, lotteries prevent small differences from drastically affecting outcome” (Persad, et al 2009: 423-431). Some other people yet support lottery allocation because “each person’s desire to stay alive should be regarded as of the same importance and deserving the same respect as that of anyone else; and that

practically, lottery allocation is quick and requires little knowledge about recipients. Finally, lotteries resist corruption”(Broome 1984; 95: 38–55; Ramsey 2002; Harris 1985).

Further, it is clear that lottery may not be a good option in allocating scarce medical interventions for the reasons that:

The major disadvantage of lotteries is their blindness to many seemingly relevant factors. Random decisions between someone who can gain 40 years and someone who can gain only 4 months, or someone who has already lived for 80 years and someone who has lived only 20 years, are inappropriate. Treating people equally [in this case] often fails to treat them as equals (Stein 2002:212–45; Elhauge 1994:82, Dworkin 2002).

### ***First-come First-served***

This is also called the ‘waiting time’ criterion. In this case, the available resources go to those that queue for them first. However, this principle is widely believed to be unfair. According to Daniels Norman, “It favours people who are well-off, who become informed, and travel quickly, and can queue for interventions without competing for employment or child-care concerns” (Persad, et al 2009: 423-431). Further this criterion of allocation is weak because it is not impervious to corruption. Hence, many out-rightly reject this criterion for the reason that it allows morally irrelevant qualities – such as wealth, power and connections – to decide who receives scarce interventions, something that makes it typically flawed.

### **Prioritarianism**

Another set of moral principles that has been proposed for consideration in allocating scarce medical interventions comes under what is known as prioritarianism. According to prioritarians, “A benefit morally matters more the worse off the individual to whom it

accrues”(Hotlug 1998:132). Unlike egalitarians, prioritarians are not concerned about equality as a relation; instead, they are concerned with absolute levels of individual welfare. According to prioritarianism, a benefit that falls at a particular level of welfare has the same moral value no matter what levels other individuals are at. And the lower this particular level is, the greater the value of the benefit (Hotlug 1998:132). Hence, prioritarianism is based on the view that distributive justice requires a special concern for the worst off. According to John Rawls’ *Difference Principle* in his *Theory of justice*, “you can tell the justice of a society by how it treats its least well-off members. This concern is often understood to reflect a concern for equality—in particular, equality in outcomes or welfare between people” (Brock, Wikler 2005). And when applied to the health care discourse, this principle takes the form of a concern for reducing inequalities in health between persons or groups.

In the allocation of scarce health resources, priority to the worst off is seen as a favourable principle because, it is believed, “the worse off that people are, the greater is the relative improvement that a given size of [health] benefit will provide them, so the more the benefit may matter to them. Alternatively, the greater the undeserved health deprivation or need that an individual suffers, the greater is the moral claim to have it alleviated or met (Brock, Wikler 2005).

However priority to the worst off might be justified, there arise disagreements within this very principle. One common disagreement within this principle is the issue of who the worst off are. This disagreement has been exemplified that “In the context of resource allocation in health care, the worst off might be those who are globally worst off, those with the worst overall well-being (such as the poor), or those with the worst health (that is, the sickest)” (Brock, Wikler 2005). Yet, others think that the worst-off can be defined in terms of their age,

leading to a criterion like ‘*youngest-first*’. This distinction between different kinds of how people can be worst-off has come up because general theories of justice usually focus on people’s overall well-being, often allowing a lower level in one domain of wellbeing to be compensated for by a higher level in another domain” (Brock, Wikler 2005).

But in response to these alternative interpretations of who the worst –off are, surprisingly,<sup>6</sup> there has been wide agreement about the claim that poverty is an irrelevant factor in the definition of who the worst off are. This argument has been advanced in what has been called a *separate spheres view*. According to *the separate spheres view*, the worst off for the purpose of health resource allocation should be considered to be those with worse health (Brock, Wikler 2005). In agreement with this position, Tim Scanlon has argued that, justice in health care resource allocation demands that “for differences in level to affect the relative strength of people’s claims to help, these differences have to be in an aspect of welfare that the help in question will contribute to” (Scanlon 1997:227). It has been argued that, from a pragmatic point of view, “it may generally be too difficult, costly, intrusive, and controversial, as well as too subject to mistake and abuse, to have to inquire into all aspects of people’s overall levels of well-being” (Brock, Wikler 2005). Two alternatives have been suggested about whom the worst off should be taken to be: that is, either the youngest or the sickest.

### ***Sickest-First Criterion***

Giving priority to the sickest is derived from one of the stringent *prima facie* rules of medical practitioners known as the ‘rule of rescue.’ According to this rule, “Our moral response to the imminence of death demands that we rescue the doomed” (Brock, Wikler 2005). Hence, treating the sickest people prioritises those with worst future prospects if left untreated.

---

<sup>6</sup> In chapter four I argue that the ‘separate spheres’ view that seeks to negate poverty in the definition of who the worst off are in health, is fallacious. There is a very necessary and strong determination between health and poverty.

*Who is the sickest?* There are disagreements about who the sickest are. The controversy is especially about the timing of the sickness. For instance, most people would agree that ‘prevention is better than cure’ and may therefore be inclined to give priority to preventive interventions at the expense of curative and rehabilitative ones. This arises from the issue of whether the worst off in health are those with worse health - those who are sickest now at the time a health intervention would be provided for them, or those with worse health over time, taking into account past and perhaps expected future health (Brock, Wikler 2005). The latter would give special weight to meeting the health needs of those with long-term chronic diseases and disabilities along with immunisation programmes. Hence the question that still awaits answer is whether special priority should be given to those whose health is not worse now but is especially vulnerable to becoming worse (Brock, Wikler 2005).

This principle of allocation has been rejected for the reason that on top of its failure to take into account prognosis, it myopically bases allocation on how sick someone is at the current time, a factor that is considered morally arbitrary in genuine scarcity. There is a claim that “preferential allocation of a scarce liver to an acutely ill person unjustly ignores a currently healthier person with progressive liver disease, who might be worse off when he or she later suffers liver failure” (Brock, Wikler 2005). Hence, “favouring those who are currently sickest seems to assume that resource scarcity is temporary: that we can save the person who is now sickest and then save the progressively ill person later” (Brock, Wikler 2005). This position has been emphasised by arguing that even if scarcity were temporary it does not guarantee another chance to save the progressively ill person, and that when interventions are persistently scarce, saving the progressively ill person later will always involve depriving



others. Therefore, “when we cannot save everyone, saving the sickest first is inherently flawed and inconsistent with the core idea of priority to the worst-off” (Brock, Wikler 2005).

### ***Youngest-First criterion***

The title given to this principle can be said to be logically inconsistent with its actual content. Strict adherence to this principle’s logical outcome would lead to giving priority to a one-day-old infant against its twenty-five year old father or mother. But in actual practice, this principle gives priority, not to the youngest, but to those who lie in the age in which they have higher expectations in life, “with a much more developed personality than the infant, and has drawn upon the investment of others to begin as-yet unfulfilled projects” (Brock, Wikler 2005). Even though some have criticised this principle as age discrimination, there is wide acceptance that it is a morally relevant factor in allocating scarce health care resources because it gives a chance to the young to experience as much life as the elderly have had. Moreover, from an instrumentalist view, those still in the youth bracket are needed for the survival of the oldest and the youngest. Hence, for such reasons, youngest-first criterion is widely accepted as a relevant moral principle that can be combined with others to decide on how fairly the scarce medical and non-medical interventions can be allocated.

But whereas priority to the worst off is attractive to many, there comes up a question of how much priority the worst off should receive. It is claimed that “Giving absolute priority to the worst off is implausible because it faces the bottomless pit problem—using very great amounts of resources to produce very limited or marginal gains in the health-related quality of life of the severely ill or disabled. However, there is no apparent principled basis for determining how much priority the worst off should receive” (Brock, Wikler 2005:263).

### **Saving most lives versus life years**

Some utilitarians who, on top of aiming at maximising health utility, care about distributive concerns too, think that achieving the highest aggregate of health benefits from a given budget is best possible by saving most lives, irrespective of how long these lives will be extended by the intervention. On the contrary, other utilitarians insist that this can best be done by looking at the prognosis of the patient and estimating how many more life years will be saved or added to the life expectancy of the person who receives the scarce resources. Hence, to the former, maximising the number of lives saved is more morally compelling than maximising life years. Those who advocate for maximising lives argue, by appealing to human to autonomy that, since each life is valuable, this principle seems to need no special justification, since, moreover, it avoids comparing individual lives (Brock, Wikler 2005:263). Those who are sceptical about fairness in relying on prognosis argue that “Making a well-off person’s life better off rather than slightly improving a worse-off person’s life, would be unjust” (Brock, Wikler 2005:263). Those who advocate for saving most lives think that it is intuitively morally wrong and unfair to, for example, let five people die whose lives would have been extended by an average of five years, and give priority to one individual whose life will be extended by thirty years. This would be the logical outcome of preferring prognosis or life years to saving most lives. Yet on the other extreme, those with aversion for saving most lives at the expense of life years are concerned about how much longer these lives can be sustained. They think it is unreasonable, for example, to extend those lives, each for a week or less, at the expense of extending a life of one individual for several years.

Other than the controversies within the utilitarian principles, when applied at the macro-level of health care resource allocation, the theory faces the problem of the relationship between aggregation of health benefits and differences in costs (Brock, Wikler 2005:263). This controversy has been illustrated in the Oregon health services commission’s decision on

whether to prioritise tooth capping for 100 patients or perform appendectomies for a single patient (Hadorn 1991). From the analysis of this case, Brock and Wikler have observed that what Oregon's experience shows is that most people's sense of priorities is determined by a one-to-one comparison of the benefits of different interventions, in which case appendectomies are clearly a higher priority than tooth capping. Nord and others have revealed from an empirical study, that many people ignore the cost differences because they believe that patients should not be at a disadvantage in priority for treatment simply because their condition happens to be more expensive to treat than are other patients' conditions (Nord, Richardson, Street, Kuhse, Singer 1995). Further, according to other moral views, "individuals should confront other competitors for scarce resources as individuals, and their priority for treatment should be determined by the urgency of their individual claims to treatment" (Scanlon, 1997).

In the final analysis, "at a minimum, individuals should not be denied very great health benefits - in the extreme case, life-saving interventions - merely to provide small health benefits to a large number of other persons" (Brock, Wikler 2005:264).

### **Fair chances and best outcomes**

Related to the maximising principles is what has been called 'Fair chances and best outcomes.' According to this proposal, resources should be targeted at interventions in which they will do the most good; hence it ascribes a higher priority to those who can be helped more easily or cheaply. "This thinking in turn implies that some patients will lose out simply because their needs are more difficult or expensive to meet" (Brock, Wikler 2005:264). In their example of 50 pills with two groups of patients (100 and 50 in each group), (Brock,

Wikler 2005:264),<sup>7</sup> they recommend that to give each patient an equal chance to recover, entitlement to treatment should be awarded randomly, even if this decision will result in 17 less cures.

It has been found out, from empirical studies on the populations' attitude towards the 'fair chances' criterion, that there is a negligible difference between health care providers and the general public in their attitudes to this conflict. Most health care providers would rather favour distribution to one pill patients only, while most members of the general public insist that people should not be penalized for needing two pills (Nord 1999). A division of opinion of this kind goes to the heart of QALY or CEA, which is precisely a guide to identifying the route to the best outcomes that can be hoped for with existing resources. It also creates a dilemma for those health professionals who maintain that health policy should be based on the moral values most frequently endorsed by the population affected (Brock, Wikler 2005:264).

Further, it ought to be noted that the conflict between fair chances and best outcomes arises not only from differences in the costs of treating otherwise similar groups of patients, but also when one group of patients will receive somewhat greater benefits than another at the same cost; that the appeal of a 'fair-chances' solution is greater when the difference in cost-effectiveness between the two programs is relatively small compared with the potential gain or loss to individual patients (Brock, Wikler 2005:264). Hence, in this case it is implied that if the costs are the same and the difference between benefits to the two groups not significant, both groups should have equal chances; and if costs are the same and the difference in benefits to both groups very significant, then 'fair chances' principle can be applied.

---

<sup>7</sup> The example is a hypothetical case of 100 patients in two groups of 50 each and the clinic having only 50 pills to give out. In one group patients require one pill each to recover, while in another group each patient needs two pills. To maximise the number of cures using the 50 pills, QALY would recommend that you give the pills to the group that need one pill for each patient because in this way you would get the maximum number of cures – 50 in this case.

However, reacting to this proposal it has been argued that giving preference to the most cost-effective program also seems unjust because it compounds existing unfair inequalities. For example:

Screening slum-dwelling black men for hypertension targets the group with the highest incidence and greatest risk of premature death. However, it is more cost-effective to target well-to-do suburban white men, because they have more ordered lives, comply better, have personal doctors and the means to obtain medical services, are more educated, and are more likely to modify their lifestyles wisely. However, if the poor black men are not screened for this reason, it only compounds their existing unjust deprivation and, of course, is also in conflict with giving priority to the worst off (Brock, Wikler 2005:264).

### **Instrumentalist views**

Allocation of scarce medical resources by giving priority on instrumental grounds is taken as being pragmatic. “Instrumental value allocation prioritises specific individuals to enable or encourage future usefulness” (Brock, Wikler 2005:264). What is mainly considered here are two things: what the individual who receives care will contribute towards the well-being of others; and rewarding those that made sacrifices for the well-being of others. On this subject, Morreim has arguably added that “Responsibility-based allocation - eg, allocation to people who agree to improve their health and thus use fewer resources - also represents instrumental value allocation” (Morreim 1995:5–12).<sup>8</sup> Two suggestions have been made about how to incorporate instrumentalist concerns in the allocation of health resources. These are either by

---

<sup>8</sup> It may be dangerous to accept Morreim’s argument because it is likely to be extended to lead to consideration of individual responsibility for sickness. Considering individual responsibility for health condition in priority setting is wrong because its acceptance would downgrade almost everyone’s medical attention claim; eg, HIV patients, victims of accidents caused by reckless driving, obesity patients, malaria patients (for not sleeping under insecticide treated mosquito nets) etc.

being forward-looking by promoting social usefulness or backward-looking by rewarding social usefulness.

### ***Promoting Social usefulness***

Allocation of health resources based on promoting social usefulness can be said to be the most pragmatic criteria for the sake of sustainability of a health system. It gives priority to those whose existence is necessary for health care to be possible and sustainable. Emanuel and Wertheimer have argued that “Guidelines that prioritise workers producing influenza vaccine exemplify instrumental value allocation to save the most lives (Emanuel, Wertheimer 2006:854–55). Those who favour promoting social usefulness recognise that although this principle is insufficient on its own, “all those whose continued existence is clearly required so that others might live have a good claim to priority. Prioritising essential healthcare staff does not treat them as counting for more in themselves, but rather prioritises them to benefit others (Persad et al, 2009).

### ***Rewarding social usefulness***

On the part of rewarding social usefulness, those who propose this principle argue that “justice as reciprocity calls for providing something in return for contributions that people have made”( Macklin 2004). But whereas this criterion may be out-rightly endorsed, what may be most controversial is its extent: that is, what kind and amount of sacrifice would be enough and relevant to warrant preferential treatment? Whereas some think that organ donors alone qualify out-rightly, or even blood donors, others claim that others, for example, war veterans who took life-threatening risks to avoid disasters that might moreover impose a

heavy toll on a health system, and directly saved other peoples' lives, should also qualify on the reciprocity ticket (Brock, Wikler 2005).<sup>9</sup>

### **Allocation by 'Need'**

Yet another controversy has arisen about 'need' as a morally relevant criterion in allocating health care services. According to this principle, those with the greatest medical needs should be given priority. But whereas many might sympathise with this principle, there is wide disagreement on what counts as 'need'. In the strongest advocacy possible for this criterion, the Sir John Toby, as quoted by Cookson and Dolan, has stated that: "We don't believe there should be discrimination on any grounds other than on clinical need" (Cookson Dolan 2000). Against this position, however, "unless the concept of "clinical need" is clearly defined using substantive criteria, this principle reduces it to the rather unpalatable procedural principle that any rationing decision must be correct so long as a clinician has taken it" (Cookson, Dolan 2000). Hence, number of attempts have been made to define 'need' in relation to health care entitlement. Whereas some define need as ill health, others argue that in defining the concept of 'need' capabilities of patients' to benefit from an intervention should take precedence in determining the patients' degree of need.

### ***Need as ill health***

Three ways have been proposed on how to define 'need as ill health.' One way to define 'medical need' has been by reference to the extent of one's ill-health. "For example, it can be argued that an immediate threat to life (for example, within the next year or so) is the most urgent and pressing form of ill health, and that saving (or prolonging) life should almost

---

<sup>9</sup> Taking this principle to its logical conclusion, priority would automatically extend to the rich, those who are productive and generate money for the economy because this money is needed for the purchase of the needed technology and other medical supplies. Hence, once endorsed as a morally relevant this principle may lead to the bottomless pit problem of who should receive priority.

always take priority over enhancing life” (Harris 1985). “A second, broader definition of need as ill health would encompass immediate pain and suffering (...) as well as immediate threat to life” (Cookson, Dolan 2000). Hence, this means that “Need can be interpreted as the individual’s immediate degree of ill health” (Gillon 1986). Yet, another possibility of defining need as ill health has been proposed to consider looking at the individual’s whole lifetime of ill health rather than just his or her immediate situation (for example, ill health in the next year or so) (Cookson, Dolan 2000).

### ***Need as Capability to benefit from treatment***

The underlying argument of this principle, though not explicitly stated in most cases, is that, the clinically ill persons without chances of benefiting from the medical intervention available have no medical need! These are of course motivated by the maximising principles – that the higher the capacity to earn more QALYs, the greater and urgent the medical need.

The WHO’s preferred criterion for allocation of scarce health resources between equally sick groups or individuals is each group’s capacity to benefit from treatment. According to this principle, “If A and B are equally ill and both can be cured, but A at a lower cost than B, then A has a greater capacity to benefit than B” (Nord 2000). The same question arises in ‘Fair chances and best outcomes’. On the contrary, however, this principle is rejected and instead a direct opposite of the above position especially for the developing countries where resource scarcity is most severe, has been suggested. The reason given for this is to give all patients a reason to hope that their health needs will be met, and strict adherence to cost effectiveness criterion could result in large numbers of patients with serious and life-threatening health needs having no hope that their needs will be met (Brock, Wikler 2005).



Generally, the bottom line is that of the above-discussed ethical principles, no single principle on its own can be relied on to ensure a just allocation of health care services. A number of them must be combined, taking into account special circumstances. Given the various competing health care systems' goals especially efficiency and equity, and the fact that it is sometimes impossible to achieve both because of the scarcity of resources, it can be concluded that "... priority-setting necessarily implies a degree of trading-off between different health system goals, such that the most equitable allocation of resources is highly unlikely to be the most efficient allocation" (Hutubessy et al.; 2003). And arguing along the same line, it has been shown that "A sequential analysis of these competing criteria, however, indicates that for the allocation of public funds, priority should be given to cost effective interventions that are public goods (have no market) and impose high spill-over effects or catastrophic costs particularly in relation to the poor, [if left unsolved]" (Hutubessy et al 2003).

## **Part II**

### **The Complete lives system**

In part one of this chapter I have discussed the various ethical principles that have been suggested to govern the allocation of scarce health resources by taking distributional concerns into consideration. From the analysis it has been seen that even though these moral principles are morally valid and compelling, none of them is enough on its own to take care of all relevant ethical values that ought to be considered in a fair distribution of scarce health resources, yet others may be considered morally irrelevant. It is for this reason that Persad et al have suggested an alternative approach to the allocation of scarce health resources, called the complete lives system.

The complete lives system approach is based on the fact that at present, none of the available systems for allocating health care resources satisfy all ethical requirements for just allocation. The complete lives system is not radically opposed to the ethical principles discussed in part one of this chapter. Instead it is a recommendation that a combination of them be used to ensure a fair and efficient allocation of health resources. According to its proponents, it incorporates five of the above-discussed ethical principles: youngest-first, prognosis, save the most lives, lottery, and instrumental value (Persad et al 2009).

The complete lives system “prioritises younger people who have not yet lived a complete life and will be unlikely to do so without aid” (Persad et al 2009). Persad et al., claim that thinkers have accepted complete lives as the appropriate focus of distributive justice, shifting attention to “individual human lives, rather than individual experiences, as the units over which any distributive principle should operate in health care rationing policy (Brock, Wikler 2005). Further, “although there are important differences between these thinkers, they share a core commitment to consider entire lives rather than events or episodes, which is also the defining feature of the complete lives system” (Brock, Wikler 2005).

Whereas taken to its logical outcome *youngest-first* principle would lead to the absurdity of allocating resources to infants rather than the youthful adults, ‘complete lives system’ modifies this principle to the avoidance of such an absurdity. Consideration of the importance of complete lives also supports modifying the *youngest-first* principle by prioritising adolescents and young adults over infants. This modification to favour the youth is based on the fact that “adolescents have received substantial education, parental care and investments that will be wasted without a complete life. Infants, by contrast, have not yet received these investments. Similarly, adolescence brings with it a developed personality capable of forming and valuing

long-term plans whose fulfilment requires a complete life” (Brock, Wikler 2005). According to the legal philosopher Ronald Dworkin, (1993), “It is terrible when an infant dies, but worse, most people think, when a three-year-old child dies and worse still when an adolescent dies.

Further, realising that justification of *youngest-first* criterion being based on the amount of resources society has already put in this group may lead to giving priority to those with affluent backgrounds because they will have received more resources at that age, it is argued that the justification for modifying the complete lives systems to favour the youth does not lead to such a conclusion. Instead, “the prioritisation of adolescents and young adults considers the social and personal investment that people are morally entitled to have received at a particular age, rather than accepting the results of an unjust status quo. Consequently, poor adolescents should be treated the same way as wealthy ones, even though they may have received less investment owing to social injustice” (Brock, Wikler 2005).

Another relevant principle that defines the complete lives system is consideration of *prognosis*. The reason for this is its aim which is to achieve complete lives – hence, it would be relentless and morally unfortunate to expend society resources on individuals that would never achieve complete lives. For example, a young adult with a poor prognosis, who has had few life-years but lacks the potential to live a complete life can not receive priority. Hence, this principle too is not taken for granted. Therefore, “considering prognosis forestalls the concern that disproportionately large amounts of resources will be directed to young people with poor prognoses. When the worst-off can benefit only slightly, while better-off people could benefit greatly, allocating to the better-off is often justifiable (Rawls 1999; Parfit 1997). Some small benefits, such as a few weeks of life, might also be intrinsically insignificant when compared with large benefits” (Kamm 1993).

The *saving the most lives* principle is also part of the complete lives system. This principle, according to Persad et al, is also included in this system for the reason that enabling more people to live complete lives is better than enabling fewer (Kamm 1993; McKie, Richardson 2005).

Instrumentalist considerations are also suggested to be part of the complete lives system. Instrumentalist considerations are supported in the allocation of health resources because of the idea that in public health emergencies, instrumental values are necessary to enable more people to live complete lives. It is indeed reasonable enough that the health care staff be given priority because the ultimate logical outcome of denying them priority, is that no one else would receive health care.

Finally, lotteries are also believed to lead to justice in that allocation of scarce resources in some contexts. To ensure that small differences in the degree of ill-health does not lead to unfair choices between the affected parties, Persad et al agree with Howard (2001) and Schwappach (2002) that lotteries be used when making choices between roughly equal recipients, and also potentially to ensure that no individual—irrespective of age or prognosis—is seen as beyond saving.

According to Persad et al., the proponents of this suggestion, the complete lives system is yet complete in another way: it incorporates each morally relevant simple principle. When implemented, the complete lives system is said to produce a priority curve on which individuals aged between roughly 15 and 40 years get the most substantial chance, whereas the youngest and oldest people get chances that are attenuated. Even though the resulting

figure from the complete lives system resembles the one from the proposal made by DALY advocates; the latter justifies preference to younger people because of priority to the worst-off, while the former does so because of priority to the instrumental value. Further, the complete lives system assumes that, “although life-years are equally valuable to all, justice requires the fair distribution of them. Conversely, DALY allocation treats life-years given to elderly or disabled people as objectively less valuable” (Brock, Wikler 2005).

Finally, according to those who favour this suggestion, basing on its formulation they argue that the complete lives system is least vulnerable to corruption. It is not easy to manipulate because age can be established quickly and accurately from identity documents. Further still, allocation based on prognosis encourages physicians to improve patients’ health, unlike the perverse incentives to sicken patients or misrepresent health that the sickest-first allocation creates (Persad et al 2009).

### **Objections to the complete lives system**

The complete lives system has not passed without criticism, and yet, vehemently defended from these criticisms by its advocates. The first criticism levelled against the complete lives system is that it discriminates against older people. In this case, age-based allocation is seen as ageism. But in response to this criticism, Persad et al, argue that “Unlike allocation by sex or race, allocation by age is not invidious discrimination; every person lives through different life stages rather than being a single age” (Persad et al 2009). They add that “Even if 25-year-olds receive priority over 65-year-olds, everyone who is 65 years now was previously 25 years” (Persad et al 2009). Hence, they argue treating 65-year-olds differently because of stereotypes or falsehoods would be ageist; treating them differently because they have already had more life-years is not.

Further, they respond to the attack on the complete lives system for its alleged insensitivity to international differences in typical lifespan. The critics of the complete lives system argue that “Although broad consensus favours adolescents over very young infants, and young adults over the very elderly people, implementation can reasonably differ between, even within, nation-states. On the contrary, however, Persad et al., argue that this criticism is based on the belief that a complete life is a universal limit founded in natural human capacities, which everyone should accept even without scarcity. Instead, they explain and recommend that, the complete lives system requires only that citizens see a complete life, howsoever defined, as an important good, and accept that fairness gives those short of a complete life, stronger claims to scarce life-saving resources (Persad et al 2009).

In his disagreement with the complete lives system, Arras has argued that principles must be ordered lexically: less important principles should come into play only when more important ones are fulfilled (Arras 2005). To counter this objection, Persad et al., appeal to Rawls’ rejection of this lexical priority as inappropriate when distributing specific resources in society, though appropriate for ordering the principles of basic social justice that shape the distribution of basic rights, opportunities, and income (Rawls 1971).

One more attack against the complete lives system by Lecker and Pearlman, (1989) on one hand and Lanken (Lanken, Terry, Osborne 1997) on the other, is that its acceptance would be premature for health care because there is need to reduce waste first, and then increase spending later. However, as already seen, “complete lives system explicitly rejects waste and corruption, such as multiple listing for transplantation. Although it may be applicable more generally, the complete lives system has been developed to justly allocate persistently scarce

life-saving interventions” Persad et al 2009). They argue, in agreement with Evans, that hearts for transplant and influenza vaccines, unlike money, cannot be replaced or diverted to non-health goals; denying a heart to one person makes it available to another. Ultimately, the complete lives system does not create “classes of *Untermenschen* whose lives and well being are deemed not worth spending money on” (Evans 1997), but rather empowers us to decide fairly whom to save when genuine scarcity makes saving everyone impossible (Persad et al 2009).

By and large, the complete lives system is motivated by the ineffectiveness of the individual substantive principles since none of them recognises all morally relevant values, and some recognise irrelevant ones. QALY and DALY multi-principle systems neglect the importance of fair distribution (Brock, Wikler 2005). The complete lives system combines five morally relevant principles: youngest-first, prognosis, lottery, and saving the most lives. In pandemic situations, it also allocates scarce interventions to people instrumental in realising these four principles. Importantly, it is a framework that expresses widely affirmed values such as priority to the worst-off, maximising benefits, and treating people equally. But as seen above, the complete lives system too is not a set of perfect criteria. Ultimately the complete lives system too is believed to have some internal flaws. And it is for this reason that there has been a suggestion to the effect that the discussion and consideration of these numerous and controversial ethical principles for purposes of health resource allocation is likely to be relenting and lead to no universally and unequivocal recommendation on this subject. Therefore it has been thought as easy, to devise a system that will help bypass these controversial principles, even a combination of them (the complete lives system). This suggestion is the *Fair Procedures* approach, discussed below.

## Part III

### The Fair Procedures Approach

An alternative to the controversial substantive moral principles and the consequent *complete lives system* proposal in the allocation of scarce health care interventions has been suggested. This new suggestion purports to avoid the controversy that surrounds the substantive principles by establishing ‘fair procedures’ that would guide policy makers in choosing the most rational and fair pattern of allocating the scarce medical interventions. This has been enshrined in what has been named ‘Accountability for Reasonableness (A4R).’ In favour of A4R, Norman Daniels has controversially argued that “Accountability for reasonableness establishing a fair process for priority setting is easier than agreeing on principles” (Daniels 2000). The reason that is offered for this claim is that, in pluralist societies we are likely to find reasonable disagreements about principles that should govern priority setting. Making reference to the disagreements on the substantive principles, he exemplifies that whereas “some will want to give more priority to the worst off, some less; some will be willing to aggregate benefits in ways that others are not [willing to do]” (Daniels 2000). Hence the argument is that “in the absence of a consensus on principles, a fair process allows us to agree on what is legitimate and fair” (Daniels 2000).

According to this suggestion, four general conditions can ensure Accountability for Reasonableness. The belief about these general conditions is that once they are met, they will lead health plan enrollees, patients, and the public to respect the fairness and legitimacy of decisions by managed care organizations and public officials regarding coverage of new technologies and treatments (Daniels 2005:228-248). Generally, the four principles are summarised as follows:

**Publicity:** Decisions [regarding rationing] and their underlying rationales must be publicly accessible.



**Relevance:** These rationales must rest on evidence, reasons, and principles that plan managers, clinicians, patients, and consumers agree are pertinent to deciding how to meet diverse needs under resource restraints.

**Revisability and appeals:** A mechanism must allow challenges to limit-setting decisions, help resolve those challenges, and allow revisions in light of further evidence and arguments.

**Enforcement:** A voluntary or public regulatory process must ensure that decision makers fulfil the first three conditions (Daniels 2005:228-248).

The above conditions, in Daniels view, “can convert behind-the-scenes deliberations by public agencies and private health plans into a public - and ultimately democratic deliberation concerning how limited resources might best be used to maintain the health of populations with diverse service needs” (Daniels 2005:228-248). The other advantage with ‘fair procedures’ has been said to be that “A culture of openness would also facilitate learning among clinicians and enrollees about the need for limits on health care coverage” (Daniels 2005:228-248). Further, many people claim that the litigious public will accept no limits and the solution therefore is to change that culture through a concerted educational effort both outside and inside these institutions that deliver and finance care. If this project is to succeed, it is believed that this “Education must begin with openness about the reasons for decisions by public and private health providers and insurers. Over time, this process can spur broader deliberation by a public better educated to think about how to share medical resources fairly and its elected officials” (Daniels 2005:228-248)

**Publicity:** The suggestion of *Fair Procedures* is based on the premise that *always*, “a fair process requires publicity about the reasons and rationales that play a part in decisions. There must be no secrets where justice is involved, for people should not be expected to accept

decisions that affect their well being unless they are aware of the grounds for those decisions” (Daniels 2000). In Peter Singer et al’s empirical study on ‘*priority setting for new technologies in medicine*’, it was found that transparency was important to participants in the decisions. This broader transparency was concluded to be a hallmark of fair process (Singer et al 2000). But against this alleged logic between justice and publicity, a question may be asked: Is what makes a decision fair the fact that it has been publicized, or the fact that that decision is fair in itself? Even though publicity may be defended from the point of the patients’ right to information, it can not be every type of information, much less if that information is likely to erode public ‘trust’ in the health system. I will pursue this point later.

**Relevance:** As a measure against what has been raised against the substantive moral principles that the *Fair Procedures* suggestion tries to overcome, those who advocate for the *Fair Procedures* proposal caution that fair process must also involve constraints on reasons. The argument is that “Fair minded people—those who seek mutually justifiable grounds for cooperation, must agree that the reasons, evidence, and rationales are relevant to meeting population health needs fairly, the shared goal of deliberation” (Daniels 2000).

**Revisability and appeals:** On the need for the revision and appeals mechanisms it is suggested that “Fair process also requires opportunities to challenge and revise decisions in light of the kinds of considerations all stakeholders may raise” (Daniels 2005:228-248).

By and large, ‘Accountability for reasonableness’ is seen as a strategy of making possible the education of all stakeholders on the substance of transparency in deliberation about fair decisions under resource constraints. It facilitates social learning about limits. It connects

decision making in health care institutions to broader, more fundamental democratic deliberative processes (Daniels 2005:228-248). Hence, it has been suggested that, since we may not be able to construct principles that yield fair decisions ahead of time, we need a process that allows us to develop those reasons over time as we face real cases; and that the social learning that this approach facilitates provides our best prospect of achieving agreement over sharing medical resources fairly (Daniels 2005:228-248).

### **A critical reflection on the Fair Procedures proposal**

No doubt that the proposal of fair procedures established through Accountability for Reasonableness is appealing, mainly due to its motivation: that is, to ensure openness, transparency, justification and enforcement of what has been agreed on. However appealing this proposal seems at a glance, it has not passed without very serious challenges. The first challenge points to the complexity involved in its '*revision and appeals*' condition on one hand, the second one to its being circular, and third is its alleged compatibility with both the 'explicit' and 'implicit' rationing.

### ***Controversies and contradictions***

Highlighting the challenges that will face the 'fair procedures' proposal, particularly the condition of 'revision and appeals', Sabik, Lie (2008) have considered a number of empirical examples. One among such examples is that of Norway's *Patients' Rights Charter* in relation to patients' autonomy. Although in principle the patients have a right and means to appeal against decisions that deny them certain treatment, in practice these means are more limited than they ought to be according to Daniels and Sabin's proposal. A critical analysis of Norway's example "demonstrates that an appeals procedure that satisfies the Daniels-Sabin appeal condition, is still controversial" (Sabik, Lie 2008). "But more importantly, the choices we face when we want to make it more specific cases reveal that we need to make it more

specific reveal we need to make choices about the underlying conflict between patient interests and cost containment and about the substantive principles that are implemented in this particular system (Sabik, Lie 2008).

Against Daniel's hope of avoiding reference to the substantive principles, they reiterate that still "Reasonable people will disagree about exactly how one should strike a balance between these competing substantive concerns ... [because] different specific appeal procedures are justified by competing substantive principles" (Sabik, Lie 2008). By this very argument it is shown that Daniels and Sabin will find it extremely hard to avoid addressing the conflicts between principles that the procedural account was supposed to make unnecessary since different specific appeal procedures are justified by competing substantive principles, (Sabik, Lie 2008). In a nutshell, they conclude that:

Concerns for procedural justice should continue to play a central role in making limit-setting decisions about health care. Discussion of substantive principles that underlie decisions should be of equal concern, though. The consideration of appropriate principles cannot be left aside and replaced entirely with a procedural account that does not specifically address the underlying principles. An increased awareness of the need to address both the substantive and procedural aspects of priority setting, in part by including relevant parties early on in discussions about priorities, may lead to decisions that are legitimate and minimize disagreement among those involved, (Sabik, Lie 2008).

### ***'Fair Procedures' and the case of implicit/explicit rationing and Trust***

Accountability for reasonableness is claimed to occupy a middle ground in the debate between those calling for "explicit" and "implicit" rationing. Those who share this opinion argue that "Like implicit approaches, the 'fair procedures' approach does not require that

principles for rationing be made explicit ahead of time. But, like explicit approaches, it does call for transparency about reasoning that all can eventually agree is relevant” (Daniels 2000).

The strongest reason for implicit rationing is to maintain public trust in the system by ensuring that patients do not get to know how they are normally weighted against others. This being the case, therefore, the ‘fair procedures approach’ as seen in Accountability for Reasonableness’ is likely to find challenges in maintaining trust in a health system. *Trust*, though not discussed widely in most health care literature, is very crucial. It has been contended that in fact it would be useless if the health care system were just, yet the population do not ‘*trust*’ that it is. It is true that “*trust* in any system holds it together especially in the face of economic and other tensions, and in its absence, mechanisms of needed control are expensive, burdensome, and uncertain, [as seen in the problems that arise in the appeals procedures]. *Trust* in an important sense is a substitute for a cumbersome regulatory bureaucracy” (Mechanic 1995).

This challenge (trust) arises in the choice between explicit and implicit rationing approaches. Under implicit rationing, only health care staff would know why they allocate resources the way they do. It would also, on top of adhering to certain agreed upon moral principles, involve a lot of discretion on the part of the health care providers on how to set priorities among their patients and different populations. Conversely, the explicit rationing approach would involve setting precise procedures for rationing ahead of time and making them known to the public as the ‘fair procedures’ condition of publicity demands. And in this case, the discretion of the health care providers would be done away with since strict adherence to the set rules, which are well known by all their clients, would be expected.

Whereas many would agree to the patients' right to information and transparency of the health care system, much of the information discussed and implemented in health care rationing discourse is likely to erode *public trust* in the system, (Mechanic 1995), especially when patients are most likely to be on the losing end, as the Sabik and Lie's Norway's example implies. An interest in making rationing criteria explicit arises from the illusion that optimisation is possible, by arriving at perfect and uncontroversial principles that balance equity with efficiency. In the view of Mechanic, an implicit rationing embedded in an appropriate value framework offers the best among admittedly imperfect alternatives of competing criteria (Mechanic 1995).

Obviously, there are problems with implicit rationing; for example the likelihood of abuse health professionals' discretion. Even though this may be the case, still implicit rationing is the best solution because it reduces tensions arising from scarcity by taking into account the determination of people to receive a particular procedure (Mechanic1995). Further, the explicit rationing procedure is not fully responsive to people's perceived and real needs because it inevitably gives preference to some who care less about treatment than others who are excluded. "Thus it results in many disaffected people who are a continuing force challenging either the rules of allocation or decisions to withhold greater investment in the area" (Mechanic 1995). In Mechanic's view, generally,

Implicit rationing, despite its imperfections, is more conducive to stable social relations and a lower level of conflict. It is doubtful that tough systems of explicit rationing can be maintained, except during crises such as war, without focusing conflict and destabilising the medical care system. Explicit rationing is also likely to confront government and the political process with unrelenting agitation for budget increases (Mechanic1995).

It has further been contended that, for example, since in many 'for profit health maintenance organisations' a large proportion of the doctor's earnings depends on meeting expected cost targets, (Hillman 1987:1743-8) most patients are uncomfortable with the idea that their doctor must balance their needs against the needs of others and cost-cutting (Mechanic, Ettel, Davis 1990:14-23). And "If patients truly knew the extent of developing conflicts of interest built into existing financial and organisational arrangements, their *trust* would be very much diminished (Mechanic, Ettel, Davis, 1990:14-23). Differences made too explicit are likely to lead to resentments and conflicts. Thus, though it is possible to have an informal understanding that the same vigour of intervention for the sick old and younger patients is inappropriate, making the policy explicit on how priority is set between them, and then applying such a policy uniformly will inevitably result in acrimony difficult to manage politically (Mechanic, Ettel, Davis 1990:14-23).

## **Conclusion**

By and large, like the case with the theory of utilitarianism and its consequent QALY approach, the above-discussed allocation principles do not provide a universally accepted solution to the dilemmas faced in allocation of health interventions in a fair and efficient manner. But whereas for pragmatic reason we may tentatively endorse a system like the complete lives system because of its comparatively better attempt to balance efficiency and distributive justice, more investigation needs to be done. However, the question that now remains unanswered is whether, after the said investigation, that resulting perfect harmonisation of the substantive allocation principles and QALY approach per se would guarantee health equity in Uganda. This seems very unlikely because the discourse on harmonising QALY approach and the popular ethical principles of allocation is based on the

material conditions on the Western world which are very different from those in Uganda. For that matter, the discourse seems to ignore special circumstances in Uganda – Poverty and its influence on health equity. This is the issue I want to briefly reflect upon as a beginning of my conclusion.



## Chapter 4

### Conclusion

#### **Introduction**

In chapter one I have made three points. In the first place I have argued that Uganda is severely deprived of its moral entitlement to good health care services and this is because of the severe scarcity of resources available to the health sector. I have further shown that this form of injustice is worsened by the unequal distribution of the burdens and benefits of the system and this arrangement disproportionately negatively affects the poor. I indicated that from real priority setting practices in Uganda and the implementation there lacks systematicity in this endeavour. And for that matter there seems to be no hope that there will be equity in health in the near future, if nothing is done to change the situation.

In chapter two, I have shown that the theory of utilitarianism is so far widely used in the allocation of health resources in what is popularly known as QALY maximisation in health. I have done this by discussing the various tools and methods to arrive at the final QALYs and this has revealed that all these promote utilitarian principles of utility maximisation. I have argued that there is nothing inherently wrong with health benefit maximisation in situations of severe scarcity of resources, except if this maximisation jeopardises other equally compelling moral considerations – such as distributive justice, in the allocation of health resources. I have proved the morality of using QALYs in health resource allocation in a brief justification. I have gone ahead to show that, even though there is a morally valid and sound argument for using QALYs in health resource allocation, it is not enough to base allocations on maximising principles. I have shown this by presenting some challenges that face QALY approach and these are concerned with distributive justice.

In chapter three I have discussed other moral principles suggested to guide health resource allocation as supplements to the QALY approach. I have shown that of the many suggested principles, no single principle is enough to take care of all relevant ethical values that need to be considered in the allocation of health resources in order to balance equity with efficiency. I have further shown that even the complete lives system, though it is a very good step towards balancing equity and efficiency, it still has some challenges to overcome. Finally I discussed another suggestion for ensuring justice in health resource allocation, called the Fair Procedures approach which is enshrined in what is called Accountability for Reasonableness. I have argued that this project is implausible without making reference to the discussion of the substantial ethical principles that it seeks to make unnecessary, and also the complexity in its 'appeals procedure'.

In this conclusion, I wish to reiterate the point that, all in all, in situations of severe scarcity it is a good idea that health systems achieve the highest possible health benefits from the scarce resources at their disposal, although this is not the only important value of the health system. Hence, equity concerns should be used to mitigate efficiency's extremism and the resulting injustice. However, I argue that in the case of Uganda, even though it is important that the dilemmas regarding the discussed principles be resolved, this is still not enough to achieve equity. The reason is that the whole discourse on these moral principles, seem to be based on a subtle and yet wrong assumption that all health services are financed by the public sector, and therefore the only thing needed to achieve equity is sharing those resources equitably. I emphasise that, even though balancing health benefit maximisation with fairness in the distribution of the available *public* resources is good, this is not good enough to guarantee equity in Uganda. The reason is that the discourse misses out on the fundamental cause of health inequities in Uganda, which is poverty and the financing mechanism used in the system.

Hence, it is necessary to focus on the needs of the financially poor because they are disproportionately adversely affected in the current system, by spending a large proportion of their income on health. I conclude that, developing an equitable financing of the health care system which takes into consideration the needs of the poor should therefore be a key priority. Before making my final conclusion, I will first make a point about the relationship between poverty and inequity in health and how this is missed in the QALY approach, the substantive ethical principles, and the fair procures approach. It is this point that will build the case for the conclusion that, ignoring the issue of poverty in addressing inequity in health, and instead turning the whole attention to the discussion of QALY approach and principles would be good, but not good enough to ensure health equity in Uganda.

### **Poverty and inequity in health**

As opposed to what the '*separate spheres view*' advocates argue, as earlier seen, there is need to consider the needs of the poor in the way health care is rationed. According to the '*separate spheres view*', for the purpose of health resource allocation based on priority to the worst-off, poverty is an irrelevant factor in the allocation of health resources, particularly in the definition of who the worst off are. On the contrary, generally in the developing world, inequity in health is caused and worsened by factors related to poverty. Some of these poverty-related factors are: unequal access to health care, unequal chances of being ill or healthy between social groups, unequal distribution of the incidence of the burden of disease and unequal distribution of the social consequences of ill health such as poverty which leads back to ill-health, leading to a vicious circle of ill-health and poverty. All these features of health inequity work against the poor members of society. Hence, there is a strong spiral causal relationship between poverty and inequity in health.

In *Health for some*: ..., it has been argued that, “When someone has no choice in his living or working conditions, then any resulting ill-health or lack of informed access to potential remedies can be judged unfair” (Edejer 2010). Hence, “equity in health thus implies a society’s commitment to individuals’ being equally capable of achieving good health outcomes and is conditional on respecting the diversity and autonomy of these individuals and achieved through taking action for the health of unfairly disadvantaged people [especially the poor] (Edejer 2010).

When it comes to the incidence of the burden of disease generally, it has been found that despite the limitations of proxy data in measuring inequity, there is a compelling picture of the widespread prevalence of inequities in health against the poor. This is revealed in the reanalysis of the 1990 Global Burden of Disease data which showed that communicable diseases cause 47.3% of deaths and 49.8% of disability-adjusted life years’ (DALY) loss shouldered by the poorest 20% of the population, whereas the richest 20% bear only 4.2% of deaths and 2.6% of DALY loss caused by communicable disease. Other health indicators show differentials of 2- to 10-fold between rich and poor (Edejer 2010).

Further, the effects of poverty on the health of individuals can easily be ascribed to its social consequences in feelings of risk, powerlessness, vulnerability due to inability to afford health care, and low self-esteem, as well as to the absolute effect of material deprivation. All these phenomena deepen the levels of inequity in health between social classes especially between the rich and the poor. It is noted also that according to empirical evidence not only the incomes of individuals but also the distribution of their incomes within a society affects their health. Thus, in addition to the absolute impact of material deprivation, a socioeconomic gradient has an independent effect on health. Some have advanced the loss of social capital

(the cohesion and solidarity of a society) as a plausible mechanism to explain many deleterious health effects (Edejer 2010).

The available evidence on the impact of illness and health care costs at household level clearly demonstrates that the most vulnerable households face enormous constraints in accessing care when they are required to pay user fees, particularly where geographic access is poor and other costs of treatment seeking are high (e.g. for transport). With the high levels of poverty throughout Uganda, household livelihoods are so fragile that if a member needs to use health services and pay fees at the time of service (whether to a public or private provider), the household may have to take actions to access cash that could lead to further impoverishment.

It has been evident so far that out-of-pocket payment for health care has disastrous consequences for the poor as far as access to health care services is concerned (McIntyre et al 2008:871–876). The evidence about the adverse consequences of user fees for households' livelihoods is so overwhelming that even the arch protagonist of user fees in the 1980s and 1990s, the World Bank, has acknowledged that “Out-of-pocket payments for health services – especially hospital care – can make the difference between a household being poor or not” (Claeson et al 2001). For that matter it has been indicated that alternative financing mechanisms may be preferable. As a result of all this, there have been growing calls for removal of user fees at public sector facilities in Africa, particularly at the primary care level. Whereas Uganda has adhered to the call of scraping user fees in all government health facilities, this has yet engendered other challenges that have kept health inequities unchanged and seemingly going worse since lack of essential medicines in public facilities is worsening and reliance on the private sector is on the increase.

### **The missing link**

The above discussed approach and substantive ethical principles of allocation miss out on one crucial issue that Uganda needs to address in order to reduce inequity in health, to the extent that a discourse on them alone can never guarantee health equity in Uganda. This missing link is the effect of poverty and wide income inequalities on equity in health. And amidst these two (poverty and income inequality), 50% of health services are financed out-of-pocket by households. Therefore ensuring equitable allocation of the available *public* health budget resources per se will not be enough to achieve equity, since the poor can not afford to pay the 50% for health care services which are not covered by the state.

The QALY approach is entirely concerned with maximising health benefits from the scarce resources at the public's disposal and nothing more. On the other hand, other substantive allocation principles are more concerned with how equitable is the distribution of the scarce resources at the disposal of the public sector as if this is the only health-financing mechanism all systems rely on. Very limited efforts, if any, are made towards exploring the fundamental causes of inequity in health especially in developing countries where there is a lot out-of-pocket financing of health services- even the basic ones. This confirms the fact that in all these approaches and principles there is an implicit, yet wrong assumption, that all health care received by the population is financed by the public sector and there is no payment of user-fees or any other form of out-of-pocket financing of health services. It is this assumption that may lead to a wrong conclusion that a just health system is one that justly allocates public resources, implying that this is the only determinant of equity in health.

Hence, the key issue that is missed in these approaches is how poverty and health care financing mechanisms affect equity in health care, especially in a developing country like Uganda. The consequence of all this is that the needs of the financially poor are ignored as well as the financial consequences of disease to the poor. All this leads to a vicious circle of ill-health from lack of access to health services, catastrophic payments for health services that plunge households into poverty, and then poverty leading to ill-health again. This situation steepens the health gradient between the rich and the poor. Hence, considering the situation in most developing countries (Uganda) there is need to pay attention health care financing and its impact on equity.

### **Recommendations**

Currently Uganda is faced with great constraints and challenges in relation to health care financing. This has caused and worsened inequities in health. For that matter, therefore:

- Basing on the perspective of pursuing financing mechanisms and schemes that will improve equity and alleviate poverty, rather than contribute to further impoverishment of vulnerable households thereby mitigating inequity in health, there is need to devise new financing mechanisms that will take into account the financial needs of the poor.
- These schemes must guarantee financial protection, i.e. should ensure that no one who needs health services is denied access due to inability to pay and households' livelihoods should not be endangered by the costs of accessing health services. To make this possible health, care financing contributions should be separated from service utilisation, which requires some form of pre-payment.

- Health care financing contributions should be distributed according to ability-to-pay. In particular, progressive health care financing mechanisms (i.e. where those with greater ability-to-pay contribute a higher proportion of their income than those with lower incomes) should be prioritised.
- Cross-subsidies in the overall health system should be promoted.
- Strategies to ensure that financial resources are translated into universal access to health services should be devised. This means that all individuals should be entitled to benefit from health services through one of the funding mechanisms in place

## **Conclusion**

The Uganda health system, like all health systems outlines efficiency and equity, as the most important aims that will guide the allocation of health resources. Although the main aim of this work was, in the final analysis, to explore the possibility of ensuring justice in health care in Uganda, part of the concern of the concern has been on balancing concerns of equity and efficiency. This is because ‘goodness’ and ‘fairness’ are the two most robust aims of all health systems. Hence, as regards the choice between promoting equity or efficiency, it is not a better choice to sacrifice the fairness objective (justice/equity) for goodness (efficiency) objective in health. A balance needs to be aimed at especially for the sake of the poor.

One of the crucial points to take note of in this work is consideration of how the major moral principles of allocation of health resources and QALY analysis of health policy ignore the fundamental source of inequity in health. From the analysis, it has been realised that due to severe shortages of health care resources in Uganda what occupies most health care



professionals and researchers is how to increase funding for the sector and achieve efficiency – according to most reports and recommendations made by the sector. Hence, this shows that when funding is so severely constrained, it is tempting to pay more attention to how to increase funding, maximise health benefits and save money, and this leads to relegating concerns of how equitably these resources are raised and allocated. But it should be noted that the concerns of equity in health are necessitated by the fact of scarcity of resources. Hence, scarcity in this case should be taken as a constant and then pursue equity nevertheless.<sup>10</sup> So, scarcity of resources should not divert attention from concerns of equity but instead make equity concerns take a centre stage in health care discourse since it is then that very stringent choices regarding health care rationing have to be made.

It has been shown that Uganda is so severely deprived in terms of health entitlement and this is due to very insufficient funding to the sector. This situation of insufficient funding has had a number of implications especially on the financing mechanisms of health services in particular for the poor. The first implication is that the health sector can not afford to finance what it regards as the minimum health care for the population. The second is that there is a lot of reliance on the private sector and out-of-pocket payments for health services. This has made equity even harder to achieve in health since the poor are being extremely more pressed than the rich. Further, from the critical analysis of the QALY approach – the widely used criterion for rationing health resources - and the substantive ethical principles, it has been shown that there is nothing inherently morally wrong with health benefit maximisation. However, this being the case does not mean that it should be done at the expense of fairness with which these benefits are distributed. Concerns of equity should be used to mitigate QALY's extremism. Finally, given the strong determination between poverty and ill-health

---

<sup>10</sup> Justice in health is not about meeting all health needs of the population. Rather, it is about equitable sharing of the burdens and benefits of the health system – namely, how to equitably raise and distribute health resources.

with the consequent negative implications for equity in health against the poor, it is not enough, for the sake of achieving equity in Uganda, to stop at attempting to fairly and efficiently allocate resources at the public sector's disposal. Instead, for the sake of the poor, revolutionary financing mechanism for the health sector which is pro-poor needs to be developed. These financing strategies should be equitable in a sense that they involve progressive financing and cross-subsidisation. Hence, for the case of Uganda, it is necessary to focus on the needs of the financially poor because they are disproportionately adversely affected in the current system, by spending a large proportion of their income on health. Therefore, developing an equitable financing mechanism for the health care system which takes into consideration the special needs of the poor should be a key priority in Uganda.

## References

1. AHCPR Publication No. 94-0593, 1994, Management of Cancer Pain: Adults: National Library of Medicine DOCLINE Information: MED/94163199
2. Aristotle, Politics (1099a31-b6): in Nichomechean ethics, The Stanford Encyclopedia of Philosophy.
3. Aristotle, Politics (1153b17-19): in Nichomechean ethics, The Stanford Encyclopedia of Philosophy.
4. Arras, JD 2005, Rationing vaccine during an avian influenza pandemic: why it won't be easy. *Yale J Biol Med*; 78: 287–300.
5. Atkinson, MA Eisenbarth GS 2001, Type 1 diabetes: new perspectives on disease pathogenesis and treatment. *Lancet*; 358: 221.
6. Bentham, J 1781, An introduction to the principles of moral and legislation
7. Braveman, P Gruskin , S 2003, Bulletin of the World Health Organisation, 81 (7).
8. Brock, D Wikler, D 2005, Ethical Issues in Resource Allocation and New Product Development. In Jamison, Dean et al, Disease Control Priorities in Developing Countries, Second Edition, Oxford University Press.
9. Brock, D Wikler, D 1998, Egalitarianism and the Levelling Down objection: Oxford Journal, Oxford University Press: Analysis
10. Broome, J 1984, Selecting people randomly, *Ethics* 95: 38–55.
11. Burstrom, Johannesson, M Diderichsen, F 2006, "A comparison of individual and social time-trade-off values for health states in the general population". *Health Policy* 76 (3): 359–370.
12. Bush, JW et al 1973, Health Status Index Cost-effective analysis of PKU In: Berg RL (ed).

13. Bush, JW Fanshel, S Chen, MM 1972, Analysis of a tuberculin testing program using a health status index. *Journal of Socio-Economic Planning Sciences* 6:49–69.
14. Busingye, C 2011, Uganda child and Maternal mortality still high – UNICEF: in the New Vision, Tuesday, 6<sup>th</sup> April 2011.
15. Cleason, M Griffin, T et al 2001, Health, nutrition and population. IN BANK, W. (Ed.) *Poverty Reduction Strategy Papers' Sourcebook*. Washington, World Bank.
16. Cookson, R and Dolan, P 2000, Principles of Justice in health care rationing: in the *Journal of Medical Ethics*; 26:323–329.
17. Crisp, R 2009, Priority to the Worse off in the allocation of Health Care: St. Anne's College, Oxford Uehiro Centre for Practical Ethics, University of Oxford.
18. Daniels, N 2000, Accountability for reasonableness establishing a fair process for priority setting is easier than agreeing on principles, *BMJ* 321: 1300 doi: 10.1136/bmj.321.7272.1300.
19. Daniels, N 2005, Fair process in patient selection for antiretroviral treatment in WHO's goal of 3 by 5. *Lancet*; 366: 169–71.
20. Daniels, N 1993, "Rationing Fairly: Programmatic Considerations." *Bioethics* 7 (2–3): 224–33 1993.
21. Dolan, P 2002, John Abel Olsen, Distributing Health Care: Economic and Ethical Issues. Oxford University Press, Oxford New York.
22. Doyal, L 1998, Public Participation and moral quality of health care rationing; in *Quality in Health Care* 7:98–102
23. Drummond, M McGuire, A 2001, *Economic evaluation in health care. Merging theory with practice*. Oxford: Oxford University Press.

24. Drummond, M Sculpher, M Torrance, G et al 2002, *Methods of the economic evaluation of health care Programmes*, Third edition. Oxford University press.
25. Drummond, M Torrance, T Mason, J 1993, Cost–effectiveness league tables: More harm than good? *Soc Sci Med* 37:33-40.
26. Dworkin, RM 1993 Life’s dominion: An Argument about Abortion, Euthanasia, and Individual Freedom: *Cambridge Quarterly of Healthcare Ethics*; CQ [0963-1801] Campbell yr:1994 vol:3 iss:2 pg:303 -306.
27. Dworkin, RM 2002, *Sovereign virtue: the theory and practice of equality*. New York: Harvard University Press.
28. Elhauge, E 1994, Allocating health care morally. *Calif Law Rev* 82: 1449–1544.
29. Evans, JG 1997, The rationing debate: Rationing health care by age: the case against. *BMJ* 314:822.
30. Fleck, LM 1994, Just Care: Health Reform and Health Care rationing: in *The Journal of Medicine and Philosophy* 19:435-443.
31. Fleming, C et al 1993, A decision analysis of alternative treatment strategies for clinically localized prostate cancer. *JAMA* 269:2650-8.
32. Leurbaey, M 2001, *Equity Versus Priority: How relevant is the distinction?* University of Pau.
33. Franco, S 2006, Calculating QALYs, comparing QALY and DALY calculations: *Health Policy and Planning* 21(5):402-408; doi:10.1093/heapol/czl018.
34. Fanshel, S and Bush, JW 1970, A health-status index and its application to health-services outcomes. *Operations Research* 18:1021–66.
35. Gillon, R 1986, *Philosophical medical ethics*. Chichester: John Wiley & Sons.
36. Gold, MR Siegel, JE et al (editors) 1996, *Cost–effectiveness in health and medicine*. Oxford: Oxford University Press.

37. Government of Uganda, Ministry of Health, 2009, *Human resources for health bi-annual report*. Kampala: Ministry of Health.
38. Government of Uganda, MoH, 2008, Annual sector performance report (2007/2008), Government of Uganda, Kampala.
39. Government of Uganda, MoH, Health Sector Strategic plan ii 2005/06 – 2009/10 Vol. 1:14).
40. Government of Uganda, MoH, 2010 The Health Sector Strategic Plan iii, Kampala Uganda.
41. Government of Uganda, MoH, 2009, National Health Policy: Reducing poverty through promoting health.
42. Government of Uganda, MoH, Ministry of Health, Annual Health Sector Report, FY 2008/2009.
43. Government of Uganda, MoH, 2002, Uganda National Drug Policy, Ministry of Health.
44. Government of Uganda, MoH, 2010, Report on Mid-Year Review of the Health Sector Performance, Financial Year 2009/10, July to December, January 2010.
45. Government of Uganda, MoH 2007, Public expenditure review, 2007, 2004/05 – 2006/07.
46. Groome, PA Hutchinson, TA Tousignant, P Hanley, JA 1999, The repeatability of three methods for measuring prospective patients' values in the context of treatment for end-stage renal failure. *J Clin Epidemiol* 52(9):849-60.
47. Hadorn, D 1991, "Setting Health Care Priorities in Oregon." *Journal of the American Medical Association* 265 (17): 2218–25.
48. Harris, J 1987, QALYing the quality of life," *Journal of Medical ethics* 13 :17).
49. Harris, J 1985, *The value of life*: London: Routledge & Kegan Paul.

50. Hiroes, I 2009, Aggregation and the Allocation of Health Care Resources, McGill University.
51. Hobbes, T 1660, The Leviathan, Chapter xiv.
52. Hillman, AL 1987, Financial incentives for physicians in HMOs: is there a conflict of interest? *NEnglJMed* 317:1743-8.
53. Howard, DH 2001, Hope versus efficiency in organ allocation. *Transplantation* 72: 1169–73.
54. Hutubessy, R et al 2003, Generalized cost-effectiveness analysis for national-level priority-setting in health sector. In Department of Evidence for Health policy, Evidence and Information for policy, World Health Organization.
55. Jecker, NS 1989, Pearlman RA. Ethical constraints on rationing medical care by age. *J Am Geriatr Soc* 37: 1067–75.
56. Kamm, FM 1993, Morality, mortality, volume 1: death and whom to save from it. New York: Oxford University Press.
57. Syngellakis, K Arudo, E 2006, Uganda Health Sector Policy Overview Paper.
58. Krahn, MD Mahoney, JE et al 1994, Screening for prostate cancer. A decision analytic view. *JAMA* 272: 773-80.
59. Klarman, HE Francis JOS, Rosenthal GD 1968, Cost-effectiveness analysis applied to the treatment of chronic renal disease. *Medical Care* 6:48–54.
60. Lanken, PN Terry, PB Osborne, ML 1997, Ethics of allocating intensive care unit resources. Baltimore: New horizons.
61. Liss, P-E 2003, Hard choices in public health: the allocation of scarce resources. *Scand J Public Health* 31: 156–57.
62. Lube, W 2009, Aggregation in Health Resource Allocation: *Ethical Issues in Prioritisation of health Resources*, Harvard University, Boston.

63. Macklin, R 2004, Ethics and equity in access to HIV treatment: 3 by 5 initiative. 2004.
64. Mallinga, S 2010, Ministry of Health, Ministerial Policy Statement, Kampala.
65. McGregor, M 2003, Cost–utility analysis: Use QALYs only with great caution. CMAJ 168 (4)
66. McIntyre, D et al 2008, Beyond fragmentation and towards universal coverage: insights from Ghana, South Africa and the United Republic of Tanzania: in the *Bulletin of the World Health Organization* 86:871–876.
67. McIntyre, D Gilson, L 2005, Equitable health care financing and poverty challenges in the African context: paper presented to Forum 9, Global Forum for Health Research Mumbai, September 12-16th, 2005.
68. McKie, J 2005, Richardson J. Neglected equity issues in cost- effectiveness analysis, Part 1: severity of pre-treatment condition, realisation of potential for health, concentration and dispersion of health benefits, and age-related social preferences. Melbourne: Centre for Health Program Evaluation.
69. Mechanic, D 1995, Dilemmas in rationing health care services: the case for implicit rationing. King's Fund Institute, London W2 4HT BMJ 310:1655-9
70. Mechanic, D Ettel, T 1990, Davis D. Choosing among health insurance options: a study of new employees. *Inquiry* 27:14-23.
71. Mo Molek 2001, Implementing QALYs, Hayward Group plc, Hayward.
72. Morreim, EH 1995, Lifestyles of the risky and infamous. From managed care to managed lives. *Hastings Center Report* 25:5–12.
73. Nussbaum, M 2006, *Frontiers of Justice: Disability, Nationality, Species Membership*, Belknap Harvad.



74. Nussbaum, M 1987, *Nature, Function and Capability*; World Institute of Development Economics Research of the United Nations University.
75. Nord, E 1999, *Cost-Value Analysis in Health Care: Making Sense out of QALYs*. Cambridge, U.K.: Cambridge University Press 1999.
76. Nord, E et al 1995, Maximising Health Benefits Vs Egalitarianism: An Australian Survey of Health Issues, *Soc. Sci. Med.* Vol.41, No.10 pp 1429-1437: Elsevier Science Ltd, Britain.
77. Nord, E Richardson, J et al 1995, "Who Cares about Cost? Does Economic Analysis Impose or Reflect Social Values?" *Health Policy* 34 (2): 79–94.
78. Orem, JN Zikusooka, CM 2010, Health financing reform in Uganda: How equitable is the proposed National Health Insurance scheme? *International Journal for Equity in Health*.
79. Odaga, J Lochoro, P 2006, Budget Ceilings and health in Uganda; BRAP06002.
80. Parfit, D 1997, *Equality and priority*, Blackwell Publishers, Oxford UK. *Ratio* 10: 202–21.
81. Persad, et al 2009, *Principles for allocation of scarce medical interventions*. Department of Bioethics, the Clinical Centre, National Institutes of Health, Bethesda, Maryland, USA. *Lancet* 373: 423–31
82. Pinto, JL P 1997, Is person trade off a valid method for allocating health care resources? In *Health Economics* Vol. 6 pp 78-81.
83. Pliskin, et al 1980, Utility functions for life years and health status. *Operations Research* 28: 206–24.
84. Ramsey, P 2002, *The patient as person: exploration in medical ethics*. New Haven, CT: Yale University Press.
85. Rawls, J 1999, *A theory of justice*. Oxford: Oxford University Press.

86. Read, JL Quinn RJ, et al 1984, Preferences for health outcomes. Comparison of assessment methods *Med Decis Making* 4(3):315-29.
87. Republic of Uganda, Ministry of Finance, Planning and Economic Development: 2007, 5-Year National Development Plan for Uganda Poverty Eradication Action Plan; Revision Process 2007/8. Concept note on the revision process.
88. Republic of Uganda, Health Sector Ministerial Policy Statement Financial Year 2009/10.
89. Scanlon, TM 1997, *What We Owe to Each Other*. Cambridge, MA: Harvard University Press.
90. Schwappach, DLB 2002, Resource allocation, social values and the QALY: a review of the debate and empirical evidence. *Health Expectations* 5: 210–22.
91. Singer, PA et al 2000, Priority setting for new technologies in medicine: qualitative case study. *BMJ* 321: 1316 doi: 10.1136/bmj.321.7272.1316.
92. Smith, KJ, Roberts MS 2000, The cost–effectiveness of sildenafil. *Ann Intern Med* 132:933-7.
93. Starfield, B 2006, State of art in research on equity in health. *Journal of health politics, policy and law* Vol. 31, No 1, Duke University Press.
94. Stein, MS 2002, The distribution of life-saving medical resources: equality, life expectancy, and choice behind the veil. *Soc Philos Policy* 19: 212–45.
95. Tang, M-X, Jacobs, D 1996, Stern Y, et al. Effect of oestrogen during menopause on risk and age at onset of Alzheimer’s disease. *Lancet* 348: 429.
96. Temkin, LS 2009, *Ethical Issues in prioritisation of Health Resources*, Harvard University.
97. The Constitution of the Republic of Uganda, 1995.

98. The World Factbook 2003 archive Note: Per capita values were obtained by dividing the GDP (official exchange rate) data by the Population data.
99. Beauchamp, TL Childress J 2001, Children, Principles of Biomedical Ethics; 5<sup>th</sup> ed., Oxford University Press, New York.
100. Uganda Bureau of statistics, 2006 Uganda National Household Survey 2005/2006 – Report on Socio-economic module: Kampala, Government of Uganda.
101. UNDP Inequality in income or expenditure / Gini index, Human Development Report 2007/2008.
102. UNICEF, 2009, The State of the World's Children: Maternal and New Born Health; pp 113 -154
103. Volk, RJ Cantor, et al 1997, Preferences of husbands and wives for prostate cancer screening. *Arch Fam Med* 6:2-78.
104. WHO, 2006 Mortality Country factsheet.
105. WHO, 2000, The Abuja Declaration and Plan of Action; The African Summit on Rollback Malaria, Abuja, (WHO/CDS/RBM/2000.17.
106. Yolanda, BV Sculpher M 2008, Practical Neurology: Quality Adjusted-Life years, *Pract Neurol* 8:175-182 doi:10.1136/pn.2007.140186
107. Zeckhauser, R Shepard DS 1976, Where now for saving lives? *Law and Contemporary Problems* 40:5–45.

#### **Electronic sources**

108. Edejer TT, Health for some: Health Poverty and Equity at the beginning of the 21<sup>st</sup> Century, The international development Research Centre  
[http://idrc.ca/rpe/ev-27385-201-1-DO\\_TOPIC.html](http://idrc.ca/rpe/ev-27385-201-1-DO_TOPIC.html)

109. International Society for Equity in Health (ISEQH10.) 2000.  
[www.iseqh.org/conf2000\\_en.htm](http://www.iseqh.org/conf2000_en.htm)
110. Nation Master, Economy Statistics: GDP (Per capita) (2006) by Country  
[http://www.nationmaster.com/graph/eco\\_gdp\\_percap-economy-gdp-per-capita&date=2006](http://www.nationmaster.com/graph/eco_gdp_percap-economy-gdp-per-capita&date=2006) Accessed on 10.08.2010.
111. Nation Master, Economy Statistics: GDP (Per capita) (2006) by Country  
[http://www.nationmaster.com/graph/eco\\_gdp\\_percap-economy-gdp-per-capita&date=1962](http://www.nationmaster.com/graph/eco_gdp_percap-economy-gdp-per-capita&date=1962) Accessed on 10.08.2010
112. The World Factbook, 2010, Central Intelligence Agency, GDP (official exchange rate) & Population, accessed on April 28, 2010.
113. World Bank, 2009, Gross domestic product 2009 & Population 2009, World Development Indicators database, Accessed on July 6, 2010.
114. World Economic Outlook Database-April 2010, International Monetary Fund; Data for 2009. Accessed on April 24, 2010
115. World Health Organisation:  
[http://www.who.int/topics/millennium\\_development\\_goals/en/](http://www.who.int/topics/millennium_development_goals/en/) Accessed on 11.08.2010
116. World Health Organisation (2008) statistics for 2006:  
<http://www.who.int/countries/uga/en/> Accessed on 11.08.2010
117. WHO, country profile of environmental Burden of disease: Public health and environment, Geneva 2009.
118. WHO, Death and DALY estimates by cause, 2002:  
<http://www.who.int/entity/healthinfo/statistics/bodgbddeathdalyestimates.xls>  
[Accessed on 12.08.2010](#)

## Reading List

(1198 pages).

1. Bush, JW Fanshel, S Chen, MM 1972, Analysis of a tuberculin testing program using a health status index. *Journal of Socio-Economic Planning Sciences* 6:49–69.
2. Brock, D Wikler, D 2005, Ethical Issues in Resource Allocation and New Product Development. In Jamison, Dean et al, Disease Control Priorities in Developing Countries, Second Edition, Oxford University Press pp 259 - 269.
3. Bentham, J 1781, An introduction to the principles of moral and legislation, Chapter one (2 pages).
4. Daniels, N 1993, “Rationing Fairly: Programmatic Considerations.” *Bioethics* 7 (2–3): 224–33.
5. Daniels, N 2000, Accountability for reasonableness establishing a fair process for priority setting is easier than agreeing on principles, *BMJ* 321: 1300 doi: 10.1136/bmj.321-7272.1300. pp 1316 – 17.
6. Government of Uganda, MoH, 2010 The Health Sector Strategic Plan III, Kampala Uganda pp. 1 - 112.
7. Government of Uganda, MoH, 2009, National Health Policy: Reducing poverty through promoting health pp. 1 - 20.
8. Government of Uganda, MoH, Ministry of Health, Annual Health Sector Report, FY 2008/2009 pp.1 -58
9. Nussbaum, M 2006, Frontiers of Justice: Disability, Nationality, Species Membership, Belknap Harvad pp. 1 – 216.
10. Persad, et al 2009, Principles for allocation of scarce medical interventions. Department of Bioethics, the Clinical Centre, National Institutes of Health, Bethesda, Maryland, USA. *Lancet* 373: 423–31

11. Smith, KJ, Roberts MS 2000, The cost–effectiveness of sildenafil. *Ann Intern Med* 132:901-67
12. The Republic of Uganda, 2008, Annual Health Sector Performance Report 2007/2009. pp. 41 – 153.
13. The Republic of Uganda, 2009, Annual Health Sector Performance Report 2007/2009. pp. 5 – 104.
14. Orem, JN Zikusooka, CM 2010, Health financing reform in Uganda: How equitable is the proposed National Health Insurance scheme? *International Journal for Equity in Health* pp. 1 – 29.
15. UNICEF, 2009, The State of the World’s Children: Maternal and New Born Health; pp 113 -154
16. Nord, E Richardson, J et al 1995, “Who Cares about Cost? Does Economic Analysis Impose or Reflect Social Values?” *Health Policy* 34 (2): 79–94.
17. Volk, RJ Cantor, et al 1997, Preferences of husbands and wives for prostate cancer screening. *Arch Fam Med* 6:2-78
18. Rawls, J 1999, A theory of justice. Oxford: Oxford University Press pp 1 -101, 228 – 291, 450 -505.
19. Daniels, N - , Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers: in *Philosophy and Public Affairs* pp 303 -350.

**1198 Pages**